










University of Worcester
Association for Dementia Studies

HDRC

Housing and Dementia Research Consortium

Summary report, June 2021

HDRC survey: provisions for people living with dementia in Extra Care Housing settings in the UK

Dr Julie Barrett

Alzheimer's Society · anchor hanover · The ExtraCare Charitable Trust · hallmark care homes · Housing 21 · platform housing group · Housing LIN Connecting people, ideas and resources

Acknowledgements

The author would like to acknowledge Kiran Sole who worked as a Student Vacation Research Assistant for the Association for Dementia Studies (ADS), University of Worcester, in 2018, updating the literature review and entering the survey questionnaire into SurveyMonkey.

I would like the thank the HDRC steering group for helping to develop the survey questionnaire by suggesting topics that were of interest to them or their organisations.

I would like to thank all HDRC housing provider members and wider contacts, such as Association for Dementia Studies (ADS) contacts and the Housing Learning and Improvement Network (Housing LIN) who forwarded the survey link to the appropriate ECH managers. Finally, thank you to Housing 21 for providing some of the photographs in this report.

Address for correspondence

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

Tel: +44 (0) 1905 542531

Email: j.barrett@worc.ac.uk

Introduction

As recognised by the recent All-Party Parliamentary Group Inquiry report on housing and dementia (Twyford and Porteus, 2021), there is a growing 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 since the early 1990s are Extra Care Housing (ECH) schemes and retirement villages (sometimes known as retirement communities).

In ECH schemes and other forms of housing with care residents live independently, in a self-contained unit with its own front door, within a community that provides flexible, personalised care and support services, where a care team is onsite and care (planned and emergency) is available 24/7. Housing with care can provide opportunities for maximising independence while providing flexible, personalised care and support services (Evans, 2009). 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. In order to provide greater housing choice to older people and other people with disabilities or long-term conditions the UK government has been influential in supporting the growth of ECH and specialist housing by developing policies and guidelines, such as the HAPPI (Housing our Ageing Population Panel for Innovation) reports (Barac and Park, 2009; Porteus, 2012; Best & Porteus, 2016; Porteus, 2018) and supporting funding of ECH schemes through Government capital grants such as the ECH Capital Fund (2004-2010), Social Care Capital Grant, Affordable Housing Programme, and the Care and Support Specialised Housing Support Fund (Twyford, 2016).

There has been much debate on whether these facilities provide a suitable environment and service to residents who have dementia. There are a variety of models and approaches to the provision of care for people living with dementia in ECH, but there is a little evidence as to what provisions are in place and 'what works' best (Twyford, 2016). There is no universally accepted terminology among providers of housing with care, although Extra Care Housing appears to be the preferred term (Elderly Accommodation Counsel, 2015; Riseborough, 2015). Thus, in this report we use the term Extra Care Housing (ECH) to describe all forms of housing with care.

This report describes an online survey to explore the provisions, policies and procedures relating to people living with dementia in ECH within the UK. The overall aim was to present a more comprehensive picture of support available to people living with dementia in ECH, which will enable housing providers to assess their current schemes within the wider context and make informed decisions about how best to provide for people living with dementia. It will also provide an essential,

informed platform from which to undertake targeted research to help shape future provision.

Study aims, design and methods

Aim

The aim of the survey was to explore the provisions, policies and procedures relating to people living with dementia in Extra care Housing (ECH) settings including retirement villages.

Method

An initial scoping literature review was conducted to synthesise evidence relating to residents living with dementia in ECH settings. Topics covered included the prevalence of dementia among ECH residents, policies and procedures relating to people living with dementia, staff skills and training, facilities and activities, the advantages and challenges of supporting people with dementia in ECH, physical design of the scheme and apartments, assistive technology and other aids, partnership and joint working.

An online survey was developed and distributed to explore the provisions, policies, procedures and support services relating to people living with dementia in ECH settings across the HDRC housing provider members. The survey contained 72 questions and took around ½ hour to complete. The general topic areas covered were:

- Details of the scheme e.g. geographical location, area (urban, suburban, rural), model (integrated, separated, dementia specialist, hybrid), number of care staff, number of apartments / rooms, number of residents, number of residents with diagnosed dementia, number of residents with suspected (undiagnosed or undeclared) dementia;
- Policies, procedures and provisions for people living with dementia
- Entry criteria for people living with dementia
- Exit criteria for people living with dementia
- Suitability of ECH for people living with dementia
- Physical environment of the scheme and apartments
- Use of assistive technology and other aids
- Staff skills and training
- Challenges and successes
- Desired changes (what they would like to do differently in supporting people living with dementia and their carers)

The link to the survey was disseminated via email to managers of ECH settings using various networks and contacts including the HDRC membership, Association for

Dementia Studies (ADS) contacts and the Housing Learning and Improvement Network (Housing LIN) newsletter. Recipients in these networks were asked to cascade the survey link to ECH managers.

Response rate

The first section of questions, about the care setting, was completed by 109 respondents but this dropped to 82 for the next section on people within the scheme. The number of respondents completing the full questionnaire to the end was 71, which gives a completion rate of 65% for the whole questionnaire.

Key findings

The ECH settings surveyed were mainly based in urban and suburban areas (46% and 38% respectively), were fully purpose built and varied in size from 2 to 260 apartments (capacity 5 to 411 residents) operating at, on average, 73% of their possible total capacity. The vast majority of extra care settings (89%) used an integrated model of dementia care, with no separated models. Rented apartments were the most common (75%). The schemes and villages had wide range of facilities that, in the main, were shared with the local community.

In terms of prevalence of dementia among residents, 16% were living with diagnosed dementia and 5% with suspected but undiagnosed/undeclared dementia (21% in total). There is good correspondence between this data and the data from HDRC housing provider members and other HDRC studies. By combining the data from all these studies, we can confidently say that an average of 16% of ECH residents are living with diagnosed dementia (range 14-19%) and a further 7% with suspected but undiagnosed / undeclared dementia (range 5-9%), 23% in total (range 20-28%).

In terms of gender, 69% of residents living with dementia in the surveyed schemes were female and 31% were male.

Residents in the surveyed schemes and villages were predominantly white (92% of the total residents (n=5492) across all the settings) and heterosexual /straight (61% of respondents stated that all of their residents were heterosexual/straight). Around a quarter of the settings had residents whose first language was not English. The most common comorbidities among residents living with dementia were physical or mobility impairment, depression or anxiety, hearing loss and diabetes.

A majority (69%) of the settings supported at least 1 couple where one already had a diagnosis of dementia on moving into the scheme/village. The average number of such couples was 2 (range 1-12, mode 1), constituting an overall average of 2% of the total number of residents. The majority (74%) of such couples lived in a two bedroomed apartment and a small portion of these (10%) had requested a two bedroomed apartment but, due to lack of availability, had to take a single bedroomed one.

Almost all of the settings surveyed had individual care plans and conducted risk assessments for residents living with dementia, however 20% of the settings did not carry out individual assessment and reassessment. Reassessments for people living with dementia most often occurred at any time, if the individual's needs had changed.

Most of the respondents felt that their organisation was committed to supporting people living with dementia (94%) and the most common service provided specifically for people with dementia was information, advice and counselling although this was only offered by just under half of the settings surveyed. Only 24% offered activities tailored for people living with dementia and 11% tailored facilities.

Forty two percent of the surveyed settings did not have any specific entry eligibility criteria that stipulate those for whom the scheme is suitable and/or not suitable with reference to people living with dementia and even more (90%) did not have formal exit criteria.

The most common reasons for denying a person living with dementia entry into the ECH settings and the most common reasons for residents living with dementia leaving the schemes and villages (excluding death) were similar and related to a high level of need and risk or safety concerns (including walking with purpose) and the inability of the scheme to meet these needs and address the risks.

Negative attitudes towards resident living with dementia are occasionally seen from other residents and the most common response to this is to provide dementia education/awareness training which was considered successful in reducing the negative attitudes.

The most common reason for people living with dementia moving into ECH, according to the managers, is for safety and / or security, followed by social interaction / company / reduced isolation / reduced loneliness in ECH settings, care available onsite 24/7 and support with needs. The positive outcomes from moving into ECH for people living with dementia reflected the reasons given above for moving into ECH but by far the most common reason was social interaction / inclusion / friends / reduced loneliness or isolation.

With reference to deprivation of liberty issues, just over a quarter of the ECH schemes and villages had residents who require continuous supervision and control (an average of 18% such residents).

Just over half of respondents felt that the physical design of their ECH scheme supported people living with dementia, just under half felt that the design of the outdoor spaces supported people living with dementia and just over half felt that the design of the building helps people living with dementia find their way around. Negative building design aspects related to orientation, wayfinding and the ease with which people living with dementia can leave the premises. Negative outdoor design aspects related to not being dementia friendly, there being nothing of interest to look at or do and, again, the ease with which people living with dementia can leave the scheme grounds. Just over half of respondents (59%) stated that residents living with dementia did occasionally get lost in the building. However, the most common difficulties respondents felt were helped by the building design were wayfinding, knowing what communal rooms are for and finding their own apartment. The majority of respondents (81%) felt that the building was well lit with plenty of natural daylight and the use of colour and patterns was not confusing for people living with dementia. Not all respondents were happy with all aspects of the design of their scheme / village and they made suggestions for design changes in order to better support residents living with dementia.

At virtually all of the ECH schemes staff had received education / training in dementia awareness and care with management being the most common staff members to have such training (96% of respondents), followed by care staff (86%). All respondents felt equipped for recognising the early signs of dementia and the vast majority (90%) felt that they had sufficient knowledge to signpost residents living with dementia to support services and specialist information and advice.

The majority of respondents (65%) felt that the staff have sufficient understanding of the different needs of people living with dementia to support them effectively and have sufficient understanding and skills to work effectively with residents living with dementia and respond appropriately to the challenges these residents face.

The most common challenges for respondents were related to accessing and interacting with external supporting services, issues with family (family intervention, family understanding/denial of dementia, family expectations of ECH living and lack of family involvement), lack of time and keeping people living with dementia safe. The most common successes related to maintaining/improving independence, increasing social inclusion/interaction/engagement and ensuring/improving wellbeing/quality of life. The most common desired changes were more time to spend with residents living with dementia and more suitable/tailored activities.

Discussion and recommendations

The findings of the survey suggest that an integrated model of dementia care is the most common model used in ECH and that the majority of ECH settings share their facilities with the local community.

For the first time we can answer the question ‘what is the prevalence of dementia in ECH in the UK?’ An average of 16% of residents are living with diagnosed dementia and a further 7% are living with suspected but undiagnosed / undeclared dementia (23% with diagnosed or suspected dementia) in ECH in the UK. We can be fairly confident about the accuracy of these prevalence figures as they are based on various sources of consistent data from both individual housing providers and studies involving multiple housing providers spread throughout the UK. Knowing the prevalence of dementia in ECH is useful for future research on ECH residents living with dementia and will inform policy and decision making relating to ECH in the UK. Couples, where one already has a diagnosis of dementia, can live well in ECH schemes with the majority of these couples living in a two bedroomed apartment

although a small portion may have to take a one bedroomed apartment and an even smaller portion may be denied entry due to lack of availability of two bedroomed.

Unlike Twyford (2016), this study found that a large proportion of ECH settings do not have specific policies to help make decisions about entry or exit for people living with dementia. This suggests a need for assessment tools to help make such decisions. In ECH settings the care should be tailored to individual needs, thus as would be expected, almost all of the settings surveyed had individual care plans and conducted risk assessments for residents living with dementia. However, the fact that 20% did not carry out individual assessment and reassessment is concerning with such a progressive condition.

The most common reasons given for denying a person living with dementia entry into the ECH settings were walking with purpose / risk of leaving the building, needs or level of dependency being too great, stage of dementia being too advanced and risk or safety concerns for the person living with dementia. These findings are similar to those of Twyford's (2016) survey and may be indicative of a risk-averse care culture that can lead to exaggerated perceptions of the risks for people living with dementia, as found in the HDRC study on walking with purpose in ECH and retirement housing (Barrett, 2020).

It appears that, according to ECH managers, the primary reason people living with dementia move into ECH is for the safety and security it provides, although whether the safety and security concerns are those of the individuals with dementia or their families is unknown. The managers felt that social interaction and reductions in loneliness were the foremost positive outcomes of living in ECH.

The findings suggest that residents living with dementia can still occasionally experience negative attitudes from other residents. However, managers feel that this can be addressed successfully with dementia awareness training sessions.

Just over half of respondents felt that the physical design of their ECH scheme supported people living with dementia, just under half felt that the design of the outdoor spaces supported people living with dementia and just over half felt that the design of the building helps people living with dementia find their way around. Given the fact that the majority (83%) of the schemes surveyed were fully purpose built, these figures are surprisingly low.

Given that negative building design aspects related to orientation, wayfinding and the ease with which people living with dementia can leave the premises and the majority of respondents stated that residents living with dementia did occasionally get lost in the building, it may seem rather unexpected that the most common difficulties helped by the building design were wayfinding, knowing what communal rooms are for and finding their own apartment. However, rather than being

contradictory, these findings imply that ease of orientation and wayfinding play an important part in the dementia-friendliness of a scheme. If designed well with dementia-friendly features, the scheme can help alleviate difficulties with orientation and wayfinding experienced by people living with dementia but if designed poorly, residents living with dementia can become lost within the scheme. Extra care housing providers face particular challenges in understanding and responding to residents living with dementia who engage in walking with purpose. However, the fact that such leaving the building can be seen as a problem in ECH is indicative of a risk averse care culture that is inconsistent with the ethos of ECH living, which purports to encourage independence and choice (Barrett et al., 2020).

A positive finding was that, at virtually all of the ECH schemes, staff had received education / training in dementia awareness and care. However, this training was primarily received by management and the majority of care staff and senior staff but only half of support staff (e.g. catering, cleaning, maintenance and hairdressers), even though it is clear from the literature review that all staff have an important role to play in supporting residents living with dementia in the community within which they live. Furthermore, training for all staff on dementia awareness and support practices is recommended in the Dementia-Friendly Housing Charter (Alzheimer's Society, 2017a).

For the majority of respondents (57%) the training was dementia awareness training of either an unspecified source or the Alzheimer's Society Dementia Friends courses. It is notable that more in-depth dementia care courses, such as NVQs, University courses, LA courses, Skills for care, Alzheimer's Society Dementia champions; 2- and 3-day courses were very rare (1-4%).

Although the majority of respondents felt that the staff have sufficient understanding of the different needs of people living with dementia to support them effectively and have sufficient understanding and skills to work effectively with residents living with dementia and respond appropriately to the challenges these residents face, it is concerning that not all respondents felt that this was the case.

It is reassuring that none of the managers who responded to the survey felt unequipped for recognising the early signs of dementia and only 4% felt that their staff were unequipped. Training and guidance for employees, particularly front-line staff, to be able to identify the signs of dementia is a commitment statement in the Dementia Friendly Housing Charter (Alzheimer's Society, 2017a). The charter also states "Ensure staff are aware of advice and advocacy services locally to support people with dementia to make decisions" and the vast majority of respondents felt they had sufficient knowledge to signpost residents living with dementia to support services and specialist information and advice.

The literature review found that the quality of staff communication with people with dementia and the availability of activities and opportunities for occupation for such residents are major determinants of quality of life and health. However, the survey found that time constraints clearly create a challenge for ECH settings in supporting residents living with dementia and managers would like more time to spend with these residents and more suitable/tailored activities. Findings from the Housing 21 (2017) survey agree, with the disproportionate amount of time people with dementia require and the impact that it has on the service creating a challenge.

Other common challenges associated with residents living with dementia found in both this survey and the Housing 21 survey were safety and security concerns and working with external supporting agencies. The literature review found that it is important to have strong partnership and joint working, and integrated strategies between social care, health and housing to ensure a good quality of life for people with dementia living in ECH settings. Clearly, the relationship between the housing sector and external agencies needs to improve and there needs to be more effective partnership and joint working to ensure better support for people living with dementia in ECH.

Recommendations

To better support people living with dementia in ECH, the following recommendations can be made, based on the findings of this study:

- Providers of housing with care need to
  - Have specific policies to inform decisions about entry or exit for people living with dementia.
  - Have individual care plans and conduct regular risk assessments for residents living with dementia.
  - Challenge negative attitudes from other residents towards residents living with dementia; this can be addressed successfully with dementia awareness training sessions.
  - Ensure all staff, including support staff (e.g. catering, cleaning, maintenance and hairdressers), receive training on dementia awareness and support practices. Management, care staff and senior staff should receive more in-depth training on dementia care.
  - Consider a specialist staff role dedicated to ensuring the wellbeing of residents living with dementia.

- Increase awareness and understanding of walking with purpose among staff. Provide training to address the issue of walking with purpose being seen as a problem and equip staff with strategies to manage walking with purpose.
- Improve design of the environment for people living with dementia to support orientation, wayfinding, walking with purpose, social interaction and meaningful activity. This includes ease of access to and design of outdoor spaces.

- The relationship between the housing sector and external agencies needs to improve and there needs to be more effective partnership and joint working to ensure better support for people living with dementia in ECH.

References

Barac, M., & Park, J. (2009). *HAPPI. Housing our ageing population: Panel for innovation*. Homes and Communities Agency.

Best, R., & Porteus, J. (2016). *Housing our ageing population: Positive Ideas HAPPI3 Making Retirement Living A Positive Choice*. All Party Parliamentary Group on Housing and Care for Older People.

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

Evans, S. (2009). Housing with Care for Older People. In: *Improving Later Life: Services for Older People – what works*. London: Age UK.

Porteus, J. (2012). *Housing our Ageing Population: Plan for Implementation (HAPPI2).* All Party Parliamentary Group on Housing and Care for Older People.

Porteus, J. (2018). *Rural Housing for an Ageing Population: Preserving Independence (HAPPI4)*. All Party Parliamentary Group on Housing and Care for Older People.

Riseborough, M., Fletcher, P. and Gillie, D. (2015). *Extra care housing – what is it in 2015?* Housing LIN report. Available from: https://www.housinglin.org.uk/_assets/Resources/Housing/Housing_advice/Extra_Care_Housing_-_What_is_it_2015.pdf

Twyford, K. (2016). *Individuals with dementia living in ECH: an initial exploration of the practicalities and possibilities.* Housing LIN Report.

Twyford., K ,& Porteus., J. (2021). *Housing for people with dementia: are we ready? A report from an Inquiry by the APPG on Housing and Care for Older People*. All Party Parliamentary Group on Housing and Care for Older People