



Housing and
Dementia
Research
Consortium

HDRC Report

Prevalence of Dementia in Extra Care Housing in the UK

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Executive Summary

Estimating the prevalence of people living with dementia in extra care housing schemes is difficult. The nature of extra care housing has changed over the past 10 years and the diagnosis rates of dementia have also changed. Based on various sources of consistent data from both individual housing providers and multiple housing providers spread throughout the UK, gathered by the HDRC, we can conclude that:

- The average percentage of extra care housing residents living with a diagnosis of dementia is around 16%
 - The average percentage of extra care housing residents living with suspected but undiagnosed / undeclared dementia is around 7%
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Introduction

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

The Alzheimer's Society estimate that 850,000 people are living with dementia in UK, of which 311,730 (36.7%) are living in care homes, 57.9% in residential care homes and 42.1% in nursing homes. (Prince, 2014). The Dementia-friendly housing charter (Alzheimer's Society, 2017) states that two thirds of people with dementia in the UK live in their own home in the community, with one third living on their own, and approximately one third of people living with dementia are in a housing with care setting.

While the Alzheimer's Society estimate that 70% of care home residents are living with dementia (Thraves, 2016), the prevalence of dementia among extra care housing residents is less clear, largely because comprehensive prevalence data across all housing providers has never been gathered. Furthermore, some people living with dementia in these setting may be undiagnosed. Estimates are available. A Personal Social Services Research Unit (PSSRU) study of those moving to extra care schemes found, on average, 37% had a form of cognitive impairment, including people with mild cognitive impairment as well as those with dementia (Darton et al., 2012). The study estimated that 3.1% of residents had severe cognitive impairment. The Alzheimer's Society estimated that 8.1% of extra care housing residents are living with dementia (Prince et al, 2014). The authors noted a caution about this estimate. Although the estimate is above the level of 3.1% of people with severe cognitive impairment estimated by Darton et al (2012), it is well under what might be expected from an average population. The small-scale HDRC study conducted in 2011 (Barrett, 2012) found a range of 7-22% of residents with diagnosed dementia and a range of 2-17% with suspected onset of dementia across the 5 case study extra care schemes (10% with a diagnosis and 8% with suspected onset for the residents of all the schemes together).

There have been studies looking at prevalence of dementia in extra care housing schemes belonging to a single provider. A study conducted by University of Bradford found that 5-47% (depending on the size and age of the scheme) of residents were living with dementia (as assessed by the Mini Mental State Examination) in 10 extra care schemes belonging to the ExtraCare Charitable Trust (Brooker et al., 2009). The

study also found that formal diagnosis and staff estimates of diagnosis varied substantially across schemes.

In recent years, housing provider members of the Housing and Dementia Research Consortium (HDRC) have conducted their own in-house surveys of their extra care properties. The prevalence data from these surveys is given below.

In 2017, the HDRC and Association for Dementia Studies (ADS) conducted a study on green dementia care in accommodation and care settings (Evans et al., 2019). Part of the study involved an online survey of accommodation and care settings in the UK; the findings of the prevalence related questions in the green dementia care survey for extra care schemes / villages are given below.

In 2018 the HDRC conducted a study to explore walking with purpose in purpose in extra care, retirement and domestic housing settings in the UK, along with the perceptions and responses of staff and family carers, in order to better understand and support residents living with dementia in such settings and to develop good practice guidelines (Barrett et al, 2020). As part of the study an online survey was conducted of extra care and retirement housing settings in the UK; the findings of the prevalence related questions in this survey for extra care schemes / villages are given below.

In 2018 the HDRC conducted an online survey of the HDRC membership to understand the current state of the provisions for people with dementia within extra care settings in the UK. The link to the survey questionnaire was disseminated to the managers of extra care housing schemes/villages via various networks and contacts including the HDRC membership, the Association for Dementia Studies contacts and the Housing Learning and Improvement Network (HousingLIN) newsletter. These recipients were asked to cascade the survey link to their appropriate contacts. The findings of the prevalence related questions in this survey are given below.

Recent data from individual housing providers and HDRC studies

In 2017-2019 extra care housing providers belonging to the HDRC steering group conducted surveys of their extra care schemes. The data gathered relating to prevalence of extra care scheme residents living with diagnosed dementia and residents with suspected but undiagnosed / undeclared dementia is given in the table below.

Extra care scheme residents with:	Mean frequency (as % of total number of residents)		
	diagnosed dementia	suspected but undiagnosed / undeclared dementia	diagnosed or suspected dementia
Housing 21 (2017) No. schemes = 130 (approx.)	17	7	24
MHA (2017) No. schemes = 28	14.1	7.5	21.6
ExtraCare Charitable Trust (2019) No. schemes = 5	14.7	6.9	21.6
Anchor Hanover (2019) No. schemes = 110	15.9	8.7	24.6

Green dementia care in accommodation and care settings survey (Evans et al., 2019)

Prevalence of dementia for the surveyed extra care settings

Mean frequency (as % of total number of extra care residents)		
diagnosed dementia	suspected but undiagnosed / undeclared dementia	diagnosed or suspected dementia
19.4 (No. schemes = 67)	8.5 (No. schemes = 63)	27.9

Walking with purpose study (Barrett et al., 2020)

Prevalence of dementia for the surveyed extra care settings (No. schemes = 42)

Mean frequency (as % of total number of extra care residents)		
diagnosed dementia	suspected but undiagnosed dementia	diagnosed or suspected dementia
14.2	5.3	19.5

HDRC in-house research survey of extra care schemes (2020)

Prevalence of dementia for the surveyed extra care settings (No. schemes = 83)

	Mean frequency (as % of total number of residents)		
	diagnosed dementia	suspected but undiagnosed / undeclared dementia	diagnosed or suspected dementia
All	16	5	21
female	11		
male	5		
Transgender /other	0		

Comparing and collating the recent data

The table below contains the data for prevalence of diagnosed and suspected dementia in extra care housing from all the sources described above.

Summary of prevalence data for extra care housing

Extra care residents with:	Mean frequency (as % of total number of residents)		
	diagnosed dementia	suspected but undiagnosed / undeclared dementia	diagnosed or suspected dementia
Housing 21	17	7	24
MHA	14	8	22
ExtraCare Charitable Trust	15	7	22
Anchor Hanover	16	9	25
Green Dementia Care Study (across numerous providers)	19	9	28
Walking with purpose study (across numerous providers)	14	5	20
HDRC in-house research survey (across numerous providers)	16	5	21
Range:	14-19	5-9	20-28
Average:	16	7	23

The average percentage of residents living with diagnosed dementia in extra care housing, based on the multiple data sources above, is 16% and the average percentage living with suspected but undiagnosed / undeclared dementia is 7% (combined 23%).

When considering these prevalence figures, it is useful to know that the average age of extra care housing residents (data provided by HDRC members in 2020) is 76 (range 75-79).

Despite some of the recent surveys above involving single housing providers and others involving multiple providers spread throughout the UK (conducted by the HDRC as part of larger studies), the findings across all the surveys are in close agreement, with a range of 14-19% of residents living with a diagnosis of dementia and 5-9% living with suspected / undiagnosed / undeclared dementia.

It is notable that the figures for residents with a diagnosis of dementia are all higher than the Alzheimer's Society's estimate of 8.1% of extra care housing residents living with dementia (Prince et al, 2014); the average being twice that of the Alzheimer's Society's estimate.

Summary and conclusions

Based on various sources of consistent data from both individual housing providers and multiple housing providers spread throughout the UK, gathered by the HDRC, we can conclude that:

- The average percentage of extra care housing residents living with a diagnosis of dementia is 16%
- The average percentage of extra care housing residents living with suspected but undiagnosed / undeclared dementia is 7%
- The average percentage of extra care housing residents living with diagnosed dementia or suspected but undiagnosed / undeclared dementia is 23%.

References

- Alzheimer's Society (2017). *Dementia-friendly housing charter*. London: Alzheimer's Society.
- Barrett, J. (2012). Provision for people with dementia within Housing with Care: Case studies from HDRC Steering Group Providers. HDRC report available at: https://housingdementiaresearch.files.wordpress.com/2012/07/report-on-provision-for-people-with-dementia_v1-6_jun2012.pdf
- Barrett, J., Evans, S. and Pritchard-Wilkes, V. (2020), Understanding and supporting safe walking with purpose among people living with dementia in extra care, retirement and domestic housing, *Housing, Care and Support*, **23**(2), 37-48.
- Brooker, D. J., Argyle, E., and Clancy, D. (2009). Mental health needs of people living in extra care housing. *Journal of Care Services Management*, **3**, 295–309
- Darton, R., Bäumker, T., Callaghan, L., Holder, J., Netten, A. and Towers, A. (2012). The characteristics of residents in extra care housing and care homes in England. *Health and Social Care in the Community*, **20**(1), 87-96
- Evans, S., Barrett, J., Atkinson, T., Garabedian, C. and Russell, C. (2019) Connections With Nature For People Living With Dementia. *Working with Older People*. Available online at: <https://www.emerald.com/insight/content/doi/10.1108/WWOP-01-2019-0003/full/html>
- Housing 21 (2017). *Exploring Dementia in Housing: Extra Care*. Intranet Survey Results. Internal Data.
- Prince, M., Knapp, M., Guerchet, M., McCrone, P., Prina, M., Comas-Herrera, A., Wittenberg, R., Adelaja, B., Hu, B., King, D., Rehill, A. and Salimkumar, D. (2014). *Dementia UK*, second edition. London,UK: Alzheimer's Society.
- Thraves, L. (2016). *Fix Dementia Care: NHS and care homes*. London,UK: Alzheimer's Society.