

Extra Care Housing and Dementia

The issue

Extra Care Housing (ECH) schemes are designed to provide on-site, flexible care and support arrangements that enable older people to stay in their ECH home for as long as possible, reducing the need for placements in residential homes. This briefing was prepared for a local authority who wanted to encourage more people with dementia to access support from the scheme at an early stage, to enable them to remain in their ECH for as long as possible, through the progressive stages of dementia. The team is particularly interested in supporting people to live through progressive stages of dementia within the scheme.

What we wanted to find out

What services enable people living with dementia to live independently for longer in extra care housing?

What we did

We searched for systematic reviews scoping reviews of what services are effective, alongside qualitative syntheses and studies of people's experiences, including surveys, published since 2015. The local authority who commissioned the briefing did not want us to focus on issues related to the physical design of the ECH environment.

What we found

We found one systematic review¹, one scoping review², a longitudinal qualitative study (ECHO)^{3,4}, an All-Party Parliamentary Group (APPG) inquiry report⁵ and a report of a survey conducted by the Housing and Dementia Research Consortium (HDRC).⁶

The systematic review¹ looked at how various types of supported housing influence the lives of people living with dementia from the perspectives of people living with dementia, their supporters, and health and social care professionals. The scoping review² identified advantages and challenges within ECH in the UK for people living with dementia, based on an analysis of research published between 2000 and 2021. The ECHO study explored older people's experiences, and their perspectives on living in ECH over an 18 month period³, and how ECH can respond to the changing social care needs of residents, including those living with dementia.⁴ The APPG report was based on four inquiry sessions with experts who were looking at all aspects of ECH for older people with dementia. The HDRC survey explored the provisions, policies and procedures relating to people living with dementia in ECH in the UK.

What the evidence suggests

There was little conclusive evidence that particular services enable people living with dementia to live independently for longer in extra care housing. There was a suggestion by experts in the APPG Report that appointing dementia "champions" at executive/senior management/board level would help to demonstrate organisational commitment and ensure effective leadership and dementia readiness in extra care housing. The evidence from the studies made a number of recommendations on aspects of running services. These included:

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1. Integrated working

The evidence suggests that improved access to healthcare and other services can help to identify and manage preventable health problems.² The studies identified potential means of enhancing coordination between social care, housing and the NHS for the benefit of people living with dementia. These include:

- Co-location of health and other support services onsite (e.g permanent consulting rooms for district nurses and rooms for temporary use by GPs, Mental Health Practitioners and Social Workers).^{2,3}
- Investment in specialist dementia nurses, care navigators and advisors within ECH settings.⁵
- Facilitation of safe and independent access to amenities (such as shops, restaurants, pubs, libraries and hairdressers), wherever they are located, and in accordance with need associated with the stage.^{3,4}
- Holistic needs assessment and joint case management with housing providers for allocating accommodation and supporting transfers of care from acute hospital settings.⁵

There is an absence of policies to support decision-making regarding pathways in and out of ECH. This presents difficulties for potential and existing residents and their families as well as for staff operating in social care, housing and the NHS.^{2,3,5,6}

2. Training

The evidence suggests that it is important to provide specialist dementia training for everyone living and working in ECH schemes, including training on walking with purpose.^{2,3,4,5,6}

- For the workforce, this includes support staff (catering, cleaning, maintenance). This supports a culture of care that enables independence and management of risk. It is reported to increase the willingness of staff to manage more complex symptoms.
- For residents who do not have dementia, learning about it can help reduce stigma and support co-habitation with those who are living with or developing dementia^{4,5}.

3. Social relationships

The most positive outcome for people living with dementia who move into ECH was found to be social interaction and reduced isolation.⁶

- It is important to offer a range of activities for older people living with dementia, as well as ensuring that other activities are inclusive. The provision of physical assistance to get to activities is key².
- Opening onsite facilities as hubs for the wider community can assist social interaction².

4. Managing risk while enabling independence

The research highlighted where risks could be managed and independence enabled at different stages of dementia:

- Regular reviews and risks assessments conducted by a team who know the residents, and take a person-centred approach help with the provision of appropriate levels of support to people whose needs change as their dementia progresses.²
- Specialist roles, such as a member of staff trained to provide additional support for residents with dementia and the specific difficulties experienced in their daily living.²
- It is useful to have flexibility in staffing arrangements to respond to changes in care needs.⁴

5. A home for life

Supporting residents as their dementia advances presents significant challenges to the idea that ECH can provide a “home for life”. The evidence suggests that ECH can meet these challenges, but only through a flexible approach to the provision of care and support.^{3,4}

Conclusions

On balance, we are confident that we have included the current best evidence for this briefing. Different studies have examined the issue of living with dementia in extra care housing from different perspectives and considered a very wide range of factors.

At the present time the recommendations from these studies lack robust evidence. Commissioners are therefore unable to quantify with any accuracy what particular factors enable people living with different stages of dementia to remain living in an extra care housing for longer. However, they provide a range of ideas as to how best to operate a scheme for the benefit of all residents. Given that of all people living in extra care housing, 23% are reported to be living with diagnosed dementia, or suspected but undiagnosed dementia,⁵ this is clearly an important area for consideration.

Quality of evidence

The ECHO study^{3,4} is considered to be of high quality. The APPG on Housing and Care for Older People takes into account experts in the field and their views to make recommendations.

Further reading

Booklets, infographics and videos produced by the Dementia in Extra Care Housing Project <https://adsdementiablog.wordpress.com/demech/>

Articles, videos and podcasts produced by the Diversity in Care Environments researcher study <https://www.housinglin.org.uk/Topics/browse/loneliness-and-isolation/DICE/>.

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² Atkinson, T. J., Oatley, R. and Evans, S. (2023). Advantages and challenges of extra care housing in the UK for people living with dementia: a scoping review. *Housing, Care and Support* <http://dx.doi.org/10.1108/HCS-09-2022-0023> (pre-print)

³ Cameron, A., Johnson, E. K. and Evans, S. (2020). Older people’s perspectives on living in integrated housing and care settings: the case of extra care housing. *Journal of Integrated Care*, 28, 3 281-290. <https://doi.org/10.1108/JICA-09-2019-0040>

⁴ Evans, S., Atkinson, T. J., Cameron, A., Johnson, E. K., Smith, R., Darton, R., Porteus, J., and Lloyd, L. (2020). Can extra care housing support the changing needs of older people living with dementia? *Dementia*, 19(5), 1492-1508
<https://doi.org/10.1177/1471301218801743>

⁵ Twyford, K. and Porteus, J. Housing LIN (2021). Housing for people with dementia – are we ready? A report from an inquiry by the APPG on Housing and Care for Older People.

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https://www.housinglin.org.uk/assets/Resources/Housing/Support_materials/Reports/HCOP_APPG_Dementia_Housing_and_Care_Inquiry-LowRes.pdf

⁶ Barrett, J. (2021). HDRC survey: Provisions for people living with dementia in Extra Care Housing settings in the UK. Summary report, June 2021. Housing and Dementia Research Consortium and Association for Dementia Studies. <https://doi.org/10.1111/hsc.13618>