



Housing LIN

Connecting people, ideas and resources

Viewpoint 107

The DemECH project: Supporting people living with dementia in extra care housing



MAY 2023

Written for the Housing Learning and Improvement Network by **Dr Rebecca Oatley**, Cardiff University and **Teresa Atkinson**, Association for Dementia Studies, University of Worcester



Introduction/Background/Context

Living in the right housing can support independence, maintain social relationships, and prevent or reduce the need for additional care and support (House of Commons, 2018; Twyford & Porteus, 2021). Thus, access to appropriate housing is key to enabling and supporting a person and their family to live well with dementia.

Extra care housing is a model of purpose-built housing with on-site care and support that is designed to support ageing in place. That is, it is intended to provide appropriate levels of care and support as a person gets older and their care and support needs change. Extra care housing provides supported independent living within self-contained accommodation that often has a range shared facilities and activities on site for residents and the wider community. Schemes vary in tenure, size, location, type of provision and facilities. The Elderly Accommodation Counsel (EAC) estimates that there are approximately 620,000 units of retirement housing (including both 'independent living for older people's schemes and extra care housing schemes) in England.

At the time of writing, the government have announced an Older People's Housing Taskforce to better understand the 'push/pull' factors to boost the supply of extra care housing and other forms of retirement living communities (DLUHC/DHSC, 2023). We hope that the DemECH research will help inform their work.

Extra care housing and dementia

Approximately one fifth of residents living in extra care housing are living with dementia (Barrett, 2020). Some will have moved in after getting a diagnosis, whilst others might develop symptoms some time after moving in. Different models of extra care housing provision exist for people living with dementia, yet little is known about how best to support people to live well with dementia in extra care housing.

The most common model of extra care housing provision is **integrated**. This means that residents living with dementia live in and amongst other residents who do not have dementia. **Specialist** schemes provide extra care housing that is exclusively designed for people living with dementia. These are less common and often smaller, with fewer facilities than the larger integrated schemes. A small minority of schemes offer a **separated** wing or unit exclusively designated for residents living with dementia within a larger integrated scheme.

The DemECH project explored how different models of extra care housing could sustain the wellbeing of people living with dementia.



The DemECH project

The DemECH project was undertaken by researchers at the Association for Dementia Studies at the University of Worcester. The project was funded by the NIHR School for Social Care (grant number 102645/ER/UWTA-P180). The project set out to:

- 1) Explore benefits & challenges of extra care housing for people with dementia.
- 2) Identify factors that impact upon benefits and challenges.
- 3) Explore advantages & disadvantages of different models.

To help shape the project, a literature review was carried out which established that whilst extra care housing can promote independence, social inclusion and provide a safe and empowering place to live, each of these elements can be a challenge to deliver or be undermined by poor practice. The project also drew on information gathered via surveys from people living with dementia, family carers and adult social care commissioners.

Using this information, eight different extra care housing case study sites across England were identified. Sites were purposively selected to ensure a range of integrated, specialist and separated schemes were sampled. Furthermore, they represented schemes of different sizes (20-260 apartments) and locations (e.g. metropolitan, urban, rural).

At each site, residents living with dementia, family carers, residents without dementia, staff, social workers and adult social care commissioners were interviewed to understand their perspectives on the benefits, challenges, and experiences of living with dementia in extra care housing. In total, 100 participants took part in interviews, including 55 residents living with dementia and family carers.

An advisory group of academics, housing & social care professionals and two residents living with dementia in ECH, supported by a member of staff, helped to guide the project.

People can live well with dementia in extra care housing, but there are many variables that impact upon the experience

People can live well with dementia in extra care housing if there is sufficient support in place that is well aligned with their strengths, preferences and needs. Provision is complex but requires a person-centred approach to manage a range of variables to optimise the lived experience within extra care housing.

It is important to note that there is huge diversity in extra care housing scheme provision across the UK. Schemes show great variability in terms of tenure, size, location, dementia friendly

design and facilities. The design and size of different schemes can enable or disable a resident's independence and provide or inhibit social inclusion.

Extra care housing tends to work better when a person moves in at a point when they can familiarise themselves with a new environment, new routines and new people.

"I think people think 'oh we don't need it yet', but my husband has mild cognitive impairment. That is only going to develop... That's the time to move... because then you get to know the community, and everybody knows you for who you are"

Barbara, family carer/resident

The level of family, friend or informal care can make a big difference too. Support can be provided through social visits, assistance with shopping or food ordering, managing finances, and attending medical appointments. A key benefit of living in extra care housing is the sense of safety and security that knowing there are staff available on site can provide. The back-up may never be needed but knowing that they are there can be key in enabling informal carers to continue to provide vital care and support between planned call times.

The culture of staff and their commitment to supporting residents living with dementia can vary. Evidence from this study suggests that having a consistent team of staff is important for creating positive staff-resident relationships.

"All I can say is how does mum look when we come into see her? She looks great. The staff have lots of banter with her. She warms to that and has a laugh"

Alistair, family carer

The culture of care, leadership, training opportunities, and resourcing can all affect wellbeing outcomes for a resident living with dementia.

Some schemes have specialist dementia staff support in the guise of wellbeing officers, or community development workers tasked specifically to support and engage residents living with dementia to reduce the risks of loneliness that might result from residing in your own private flat. Alternatively, some residents at some schemes attend specialist day service provision that provides a level of stimulation during the daytime that supports them to sustain their extra care housing residency.

Different models work for different people

Findings from the project demonstrated that there were possible advantages and disadvantages to each model of provision, but there was no one-size-fits-all that provides the optimal model for extra care housing provision for people living with dementia.

Integrated schemes are the most common model and therefore, can provide much more choice in terms of location and facilities. Schemes are often larger, have more activities and facilities, and other residents without dementia can be supportive. Larger schemes also offer more choice in

terms of who you choose to spend your time with, and they can be valuable in supporting couples where one partner is living with dementia.

“when I need any help at all, like when [my husband] falls over, just pull the cord and they come up and get him up for me and yeah, then they’ll ring then for two, three days to see whether he’s fine.”

Betty, wife of Brian, living with dementia

However, larger schemes can be disorientating, difficult to navigate, and other residents might isolate or complain about a resident living with dementia based on stigmatised views of the condition. Staff in these schemes might lack specialist training and there are often lower staff-resident ratios relative to smaller, more specialist schemes.

Specialist schemes may be more committed to supporting residents living with dementia and some people suggest that feeling like ‘everyone is in the same boat’ can be reassuring. Specialist schemes are often smaller and can have a higher ratio of staff to residents, thus are better able to uphold the ethos of flexible care and support at the heart of the extra care housing vision. Staff often have access to more specialist training with respect to working with people living with dementia.

“My experience.. [specialist schemes] will support with all the cooking, keeping those skills going. In other schemes, at lunchtime, it’s a microwave meal”

Social worker

However, there remains the risk of stigma from other residents and their families even in specialist schemes. It can also be harder for providers to fill vacant flats with new residents who will help maintain the balance of care, which can be important in upholding the spirit of extra care housing.

“To be a vibrant active community, you need those people without care, or low-level needs in the building, otherwise it can feel like a residential care home”

Adult social care commissioner

A further issue in specialist schemes is that some residents with more challenging symptoms might dominate staff time, leaving other residents unable to access the level of support and stimulation required to maintain optimal wellbeing.

Separated schemes remain relatively rare. Having a separated area exclusively for people living with dementia can be beneficial in concentrating staff support and creating a smaller “local” area for a person living with dementia to familiarise themselves with. Schemes usually have optional access to the broader integrated scheme, which means many of the benefits of integrated living can also be accessed here. However, many residents in extra care housing don’t develop dementia until after they have moved in and it is unlikely to be in their best interest to move flats once they have settled. This means that many residents living with dementia do not have access to the separated specialist support.

Just as in other models of provision, residents living in a separated scheme can also be subject to stigma based on dementia. It is important to say that not all people experienced stigma, and there was evidence of other residents also being very supportive of residents living with dementia.

“There’s a stigma to dementia. I haven’t felt it too much personally, but if I was more advanced, I don’t know.”

Ron, resident living with dementia

Stigma was more likely directed at people whose symptoms were more visible, for example, walking with purpose or difficulties with communication. However, much work remains to be done in tackling the stigma of living with dementia even within specialist services.

Can extra care housing be a ‘home for life’ for people living with dementia?

Some people living with dementia will be able to live in extra care housing for the rest of their life. However, extra care housing cannot guarantee to be a ‘home for life’ for everyone.

Some people might develop symptoms or other health conditions that would benefit from more care and support than is available from staff in an extra care housing scheme. If a person is frequently distressed, displaying challenging behaviour, or is wanting to leave the scheme, but is deemed unsafe to do so, this might be the point at which extra care housing is no longer providing the level of care and support required. For these people, a move to a smaller environment with more intensive staff support might be in their best interests.

Key insight booklets

A key part of the project has been the creation of key insight booklets aimed at people and families living with dementia, organisations involved in extra care housing provision for people living with dementia, and adult social care commissioners and professionals.

The key insight booklets were created in consultation with key stakeholders, including people living with dementia, family carers, and professionals. Their input shaped the content and style of the booklets, which cover topics such as the pros and cons of different models, benefits and challenges of living in extra care housing, factors that can support living well, key lessons for practice, and case study vignettes of different people in different schemes.

These booklets are available online via the [Housing LIN](#) and hard copies can be ordered from the [Association for Dementia Studies](#).

Conclusion

Extra care housing can support a person to live well with dementia. However, there are a complex system of variables that can impact upon the relative benefits and challenges that an individual might experience. Many people still do not know that extra care housing exists, nor do they understand the level of care and support that can be provided. Extra care housing is often described as independent living, but in truth, it is independent living with support. Although staff can be onsite 24 hours a day, it is not 24-hour support and supervision. Misunderstanding this subtle difference can result in people moving in at the wrong time, which can challenge their ability to settle and live well in the scheme.

Living well with dementia in extra care housing involves ensuring a person-centred approach is provided in order that the right person can live in the right housing, with the right care and support, at the right time. The ability to live well with dementia in ECH goes beyond the type of provision (integrated, specialist, separated) and different provisions will suit different people, thus, providing choice is key. This requires investment, promotion, and sufficient resourcing of provision such that delivery of extra care housing remains true to the original vision and can provide an ideal environment in which many people living with dementia can thrive in their flat or apartment, but with an additional layer of support from the multiple systems and relationships around them.

References

Barrett, J. (2020) '*HDRC Report: Prevalence of dementia in Extra Care Housing in the UK*' Association for Dementia Studies: Worcester

DLUHC/DHSC. (2023) <https://www.gov.uk/government/news/government-unveils-taskforce-chair-to-boost-older-peoples-housing>

House of Commons (2018) '*Housing for older people: Second Report of Session 2017-2019*' Available at: <https://publications.parliament.uk/pa/cm201719/cmselect/cmcomloc/370/370.pdf> (Accessed 10 September 2021)

Twyford, K. and Porteus, J. (2021) '*Housing for people with dementia – are we ready? A report from an inquiry by the All-Party Parliamentary Group on housing and care for older people*' https://www.housinglin.org.uk/_assets/Resources/Housing/Support_materials/Reports/HCOP_APPG_Dementia_Housing_and_Care_Inquiry-LowRes.pdf

Note

The views expressed in this paper are those of the authors and not necessarily those of the Housing Learning and Improvement Network.

About the Housing LIN

The Housing LIN is a sophisticated network bringing together over 20,000 housing, health and social care professionals in England, Wales and Scotland to exemplify innovative housing solutions for an ageing population.

Recognised by government and industry as a leading 'ideas lab' on specialist/supported housing, our online and regional networked activities, and consultancy services:

- connect people, ideas and resources to inform and improve the range of housing that enables older and disabled people to live independently in a home of their choice
- provide insight and intelligence on latest funding, research, policy and practice to support sector learning and improvement
- showcase what's best in specialist/supported housing and feature innovative projects and services that demonstrate how lives of people have been transformed, and
- support commissioners and providers to review their existing provision and develop, test out and deliver solutions so that they are best placed to respond to their customers' changing needs and aspirations.

If you found this of interest, also check out the Housing LIN's dedicated dementia and housing webpages at: <https://www.housinglin.org.uk/Topics/browse/HousingandDementia/>

Published by

Housing Learning and Improvement Network
c/o PRP, The Ideas Store
10 Lindsey Street, Clerkenwell
London EC1A 9HP

Email: info@housinglin.org.uk

Web: www.housinglin.org.uk

Twitter: [@HLINComms](https://twitter.com/HLINComms)