



Extra Care Housing – a Focus on Dementia

Part 1: Moving in and out of extra care housing

This is the first of three viewpoints developed from a Doctoral Research Study on the possibilities and practicalities of people with dementia living in extra care housing. It offers a viewpoint on when extra care housing is an appropriate choice for someone with dementia, and what factors might trigger someone living with dementia in extra care housing to move out.

The second viewpoint considers an extra care scheme as a social world and how the different social groups in extra care housing can help or hinder someone living well in extra care housing.

The third and final viewpoint reviews how extra care housing operators can approach quality management to keep residents and tenants at the heart of their service within a complex regulatory environment.

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Introduction and key messages

This is the first of a series of three viewpoints for the Housing LIN developed from a Doctoral Research Study on the possibilities and practicalities of people with dementia living in extra care housing.¹ The research findings contained six key messages:

1. People with dementia can and do live well in extra care housing, but it is not appropriate for everyone.
2. It is important not to lose sight of the individual person when planning a model of extra care housing that meets the needs of all stakeholder groups.
3. What mattered to residents, staff and managers was being clear what extra care housing is (and is not), which includes having support in place for people to live as independently as possible in a well-supported community. Having person-centred and flexible but consistent care was essential.
4. A complex interaction between social worlds², the spatial design of the scheme, and organisational structure was found to be critical to how extra care communities, including those individuals living with dementia, function.
5. Operators of extra care housing, with complex partnership arrangements, can better keep older people and residents at the heart of their extra care housing model and manage the complex interaction of social worlds, spatial design and organisational structure by adopting a shared approach to quality and operational excellence.
6. The proposed model of extra care housing in the research study, and recommendation to have a shared approach to quality management, could be adopted by local extra care housing partnerships to benefit residents and other stakeholder groups.

¹ Twyford, K, 2018, People with Dementia Living in Extra Care Housing: An exploration of the possibilities and practicalities, White Rose eTheses Online.

² Social worlds theory originated from work on social groups (Thomas, 1914; Mead, 1938; Strauss, 1978a). It considers both situations and relationships (Baszanger & Dodier, 1997; Clarke & Star, 2008). It is helpful for understanding how groups develop in extra care, and how individuals are included or excluded from those groups. Social groups and social worlds theory are discussed in more detail the second Viewpoint of this series.

This first paper offers a viewpoint on when extra care housing is an appropriate choice for someone with dementia, and what factors might trigger someone living with dementia in extra care housing to move out.

The second paper considers an extra care housing scheme as a social world and how the different social groups in extra care housing can help or hinder someone living well in extra care. It can be accessed at:

<https://www.housinglin.org.uk/Topics/type/The-social-world-of-extra-care-housing/>

The third and final paper reviews how commissioners and operators of extra care housing can approach quality management to keep residents and tenants at the heart of their service within a complex regulatory environment. It can be accessed at:

<https://www.housinglin.org.uk/Topics/type/Approaches-to-operational-excellence-and-managing-the-quality-of-the-extra-care-service/>

The Dementia Friendly Housing Charter seeks to make the housing sector, including housing organisations, corporate bodies and sector professionals aware of the challenges of living with dementia so that home environments can be improved (Alzheimer's Society, 2017). These three Viewpoint papers aim to develop greater awareness of the contribution of housing to the challenges posed by dementia. They each include recommendations for those who commission, develop and operate extra care housing schemes.

Informed by a survey of extra care housing provision supported by the Housing LIN (Twyford, 2016), this research involved two extra care schemes as detailed case studies. The schemes had between 55 - 61 affordable³ apartments and were run by housing association and local authority partnerships. Forty different interviews, discussion groups and other activities were held with residents, staff, managers, developers, commissioners and other interested parties.

Background

Current understanding of housing need in later life is shaped by demographics, social policy, legislative responsibilities, and a growing but limited body of research and guidance on supporting individuals with dementia to maintain independence with appropriate levels of care. The research undertaken for this doctoral study used case studies to ask three main questions of those living and working in extra care schemes. The three questions were:

- What is extra care housing, and what does it mean to you?
- Is the extra care housing in this scheme appropriate for a person with dementia, and why?
- What modifications to the extra care housing scheme might make it easier to support individuals with dementia and their carers to live well?

The findings from this research complement the findings of the ECHO project which researched the provision of social care in extra care housing and explored how care is negotiated and delivered in extra care housing schemes for older people (Echo Project, 2018). The discussions with participants in this research revealed that individuals with dementia can and do live well in extra care housing, but there may be some exceptions and it may not be appropriate for everyone.⁴

³ Affordable extra care includes social rented, shared ownership or outright purchase provided to specified eligible households whose needs are not met by the market.

⁴ This builds on previous research which considered the suitability of extra care for people with dementia, see for example Croucher, et al., 2007; Dutton, 2010; Barrett, 2012; and Evans, S & Cameron, 2018

Is there a best time to move into extra care housing?

Participants described how it is important that individuals with dementia should still be able to navigate their way around a new environment, establish new routines, and make relationships with other people when they first move into extra care housing, although they might need support to do that. In consequence extra care housing might not always be appropriate for those people who cannot navigate their way around a new environment, establish new routines, and make relationships with other people when they are considering a move into extra care housing.

What mattered to residents, staff and managers was being clear what extra care housing is; a place where people can both live as independently as possible and take part in a well-developed and well supported extra care housing community. Participants in the research said it was imperative to have the right processes and people in place to provide personalised and flexible services for individuals living with dementia. A strong theme from the research was the importance of not losing sight of the individual person when planning a model of extra care housing that meets the needs of all stakeholder groups.

How can extra care housing best meet the needs of people living with dementia?

A model of extra care housing that could support people with dementia was developed with participants, using their experiences of living and working in extra care housing. Four inter-related themes were identified by participants.

The first theme was having a clear vision for extra care housing. Participants varied in what they thought extra care housing was, which was summarised by one staff member who said:

“Some [residents and family] have felt that it was 24-hour residential, that there would be someone popping in every hour and making sure they were ok kind of thing. Others have felt that it was just like a retirement village and it wasn't going to be for people with any kind of health problem, disability or anything. Yes, that's what they were thinking.”

The lack of clarity was echoed by residents, one of whom said:

“This is when it was independent living with support. But then that was channeled at us if we put queries in one direction. But then if we'd got something else to say, it was extra care. There was never any clarification to which actually this scheme was.”

There was agreement from all the participant groups that the extra care housing should be designed to provide a helpful environment for everyone, and that there should be the right policies in place to support residents, family, staff and other professionals to live and work well together. Managers and other senior representatives of the commissioners and operators of extra care housing interviewed also placed high priority on developing good partnerships to commission, operate and monitor viable services. **Having a process that is transparent and supports appropriate moves in and out of extra care was important to staff and managers.**

The second theme included factors that would help an individual to live well. Living well was meant being able to live independently in a supportive environment with person-centred services which maintain the rights of people and enable them to take appropriate risks. Having

the right culture was said to be essential for people to maintain relationships and their personal identity as their dementia progressed. In one focus group, a carer discussed her feelings about being part of the extra care housing community with her husband who was living with dementia.

“As I say, one of the reasons I don’t come down with him is because he’s... he talks to anybody... he’s got to stop and talk to everybody. It doesn’t matter who they are, whether they know him or not, and sometimes it’s... it’s a bit embarrassing you know, some of the things he does, and I think that’s why...”

As a result of being able to discuss her feelings, other residents were able to reassure her that her husband was a valued member of the community, and they discussed how informal events could be arranged to include him in ways that she wouldn’t find embarrassing.

The third theme was having a well-developed community. A well-developed community was described as adding value to the extra care housing schemes; it was what made a difference to people from living alone in their previous home. Development of the community involves effective working between residents, staff, and the wider community to make sure that the right facilities are available, and that people can take part as much or as little as they are able or want to. One participant talked about the extra support needed to help residents to settle in, but which is not part of their planned care package. They said:

“It is for things like, if you get a new resident, to help them come down and integrate into the group. To take them into the café, to introduce them to people, to sit with people. Which is not perhaps going to be in their support plan because once they get going it will be alright. They just need that bit of help with their routine don’t they?”

The fourth theme was having formal and informal care and support from a team of people. The teams included care staff, housing support staff, housing management staff, catering and cleaning staff, social workers and other professionals visiting people in the schemes, as well as family and residents supporting each other.

The sum of the team was greater than the individual parts and its effectiveness was influenced by strong leadership; by having skilled and competent staff, volunteers and residents⁵; by being clear about staff roles whilst at the same time reducing boundaries between the different staff groups; and by management of the capacity of people and other resources available. Staff and managers who participated in this research often referred to the concept of a floating staff member who could work across different organisations involved to provide support to individual residents. The purpose of the floating staff role was to meet unplanned or emergency care and support needs and to promote wellbeing through social inclusion, particularly important for people living with dementia.

A model of extra care housing was developed with the four themes identified by participants (see *Figure 1*). No one individual theme was thought more important than the others, but having synergy between the four should better support someone with dementia to live as well as possible.

⁵ A report and resource pack, *Making a Start*, provides information and a resource pack to help housing providers equip their workforce with knowledge and skills to work effectively with people who have dementia (Garwood, 2014); common core principles for dementia are set out in a guide to training the social care and health workforce by Skills for Care (Skills for Health & Skills for Care, 2018)



Figure 1: A model of extra care to support people living both with and without dementia

Participants also highlighted the importance of having effective communication and the right culture with a positive commitment from everyone involved in extra care housing to live and work together. These were described as the ‘glue’ that influenced how easily the four inter-related themes might come together, and how easily the resident or customer voice would be heard. Participants raised issues that were relevant to both the personal ‘care and support’ within extra care housing and the ‘management’ of extra care housing schemes.

When might extra care housing no longer be suitable for individuals living with dementia?

Staff were seen as critical in helping people with dementia live well as part of the extra care housing community. By understanding dementia and using a person-centred approach staff could provide a bridge to help individuals to maintain and reflect their personal identity in their everyday relationships with other residents. By respecting people and helping them to establish and maintain relationships with other residents, staff were also instrumental in helping people with dementia to avoid unwanted isolation and to take part in community activities.⁶

⁶ Being part of a community and the role of social groups will be explored in the second paper of this series, Viewpoint 92.

A big issue for residents, staff and managers was to manage risk and safeguarding issues. It was reported that some people living in extra care housing whose dementia had progressed might have to move out if their rights, risks and safety could not be appropriately managed. Where a person with dementia lived as part of a couple, the carer appeared to be instrumental in helping the person with dementia to remain more settled in extra care housing as their dementia progressed.

A positive approach to managing risk was more easily developed where staff and residents had an existing relationship with the person with dementia. Managing or not managing risks was seen as an issue important to the quality of life of the person with dementia and other residents. Managing differing expectations and requirements for a good quality of life is an essential part of service quality assurance.⁷ Staff, residents and managers involved recognised the difficulties caused when risks to safety become too great and a person's rights become compromised. It was notable that a common trigger for moving to another more appropriate environment is if someone cannot be effectively supported to safely navigate their way inside and outside the extra care housing scheme in the local neighbourhood.

A framework for action – keeping residents at the heart of the extra care housing service

Participants in the research talked about variation in the way services were delivered, depending principally on the leadership at the scheme. There was appreciation that staff were often willing to go the extra mile to make sure residents received an excellent service, as well as discussion about the constraints imposed by limited financial resources.

There was some understanding that constraints were driven by policy decisions underpinned by politics, local government funding, and by fair allocation of funding across different sectors. Notwithstanding the constraints there was a commitment by individuals to provide the best possible extra care housing service.

Three main issues were identified in relation to how the model of extra care housing could be delivered; the availability of support staff, effective use of space by individuals and groups helped by having a well-designed environment⁸, and how quality is managed across extra care partnerships. The first issue was the availability of support staff.⁹ Staff can help individuals living with dementia to be part of the extra care community and to live as independently as possible, but it was not always clear whose role it was. One member of staff commented:

“It’s little needs that people have that I expected the housing support worker to do... engaging them to come to groups or determining with individuals about what other needs they might have with housing... it’s not care, but it would help them with their whole life if there was more availability for that... and we’re looking to each other to bridge that gap, but nobody is....”

⁷ Service effectiveness and quality management will be explored in the third paper in this series, Viewpoint 93.

⁸ The Housing LIN's Design Hub offers guidance and examples of effective design principles and practice in specialist housing for older people: <https://www.housinglin.org.uk/Topics/browse/Design-building/>.
Design guidance specific to environments for people with dementia are also available at the Housing LIN Design and Built Environment pages: <https://www.housinglin.org.uk/Topics/browse/HousingandDementia/Design/>.

⁹ The second and third issues will be covered in the second and third papers in this series, Viewpoints 92 and 93.

There are barriers to staff support being put in place including the economic climate, resource constraints, style of leadership and culture. This research suggests that organisations with complex partnership arrangements can keep older people and residents at the heart of their extra care housing service better if they adopt a shared approach to quality and operational excellence.¹⁰ Recommendations to ensure older people are at the heart of the extra care housing service are set out in Box 1 below and include involving older people both individually and collectively, considering how older people can be empowered, making sure that any group involves those people who are relevant to the decisions that need to be made, valuing everybody's contributions and being systematic but person-centred.

Box 1: Older people at the heart of the extra care service model

DEVELOPING THE EXTRA CARE SERVICE TO SUPPORT INDIVIDUALS WITH DEMENTIA TO LIVE AS WELL AS POSSIBLE

Putting older people at the heart of the extra care service model

Involve older people both individually and collectively in developing a shared vision of the extra care model. Involve older people in local groups that influence the future development of housing and personal care services for older people. Consider how 'hard to reach' groups such as those living with dementia can be targeted on a systematic rather than adhoc basis.

Seek individual and collective representation of older people. Involvement of a community member in co-designing services for a collective group will be different from individual residents co-producing their own individually tailored services.

Consider how older people can be empowered to take part. Consider how social groups form and operate and what will help older people be included and have agency within the group. Make sure that any professional or managerial tools can be understood and used by all members of the group.

Create a balance between person and process centred approaches. Adopt an approach that allows both flexibility and consistent service development to meet the needs of the whole extra care community and specific individuals within it. Ensure partners focus on how any separate processes across organisations jointly deliver outcomes for residents.

Tailor the group to the circumstances and the decisions and actions that need to be agreed. Concentrate involvement on what outcomes need to be achieved rather than on the process of involvement itself.

Value everyone's contribution and negotiate the best outcome for everyone.

Be systematic! Ensuring older people are at the heart of an extra care service will not happen by chance. Plan how to involve older people in developing the extra care model; get on and do it; review how effective it was; analyse whether and how it can be improved.

¹⁰ Shared approaches to quality and operational excellence will be explored in the third article of this series.

Next steps – influencing policy and practice

As the research developed, aspects of extra care housing practice emerged which could be influential in how people with dementia experience life in extra care housing, and in how the attitudes of other people could change towards them. Policy and practice recommendations for extra care housing commissioners, developers and providers are set out below.

Box 2: Policy and Practice Recommendations for Extra Care

DEVELOPING THE EXTRA CARE SERVICE TO SUPPORT INDIVIDUALS WITH DEMENTIA TO LIVE AS WELL AS POSSIBLE

1) *Develop a shared vision of the extra care housing service with older people, partners and contractors*

- Keep going back to the shared vision and consider how the quality of the service will be managed across all providers to deliver an excellent service.
- For new schemes consider where it will be located and how the scheme will become part of the local community.
- Consider how the design and use of the spatial environment in the scheme will make it easy or more difficult for social groups to develop and for people with dementia to be included.
- Build and design an easy to navigate scheme from the beginning - be bold! It helps everyone.

2) *Identify how the shared vision of the extra care housing service will be realised*

- Be clear what the core services will be and the support available for unplanned or flexible care to meet the emotional and social needs of extra care residents.
- Continue to seek a balanced allocation¹¹ and consider how best to prioritise allocations to individuals living with the early stages of dementia.
- Adopt best practice for assessing individuals before the allocation panel; home visits and meeting the person are strongly recommended; make plans for individuals to be supported in their transition to their new home.
- Be clear what measures will be important in determining how well the scheme is meeting the needs of all its stakeholders including residents with and without dementia and regulatory bodies.
- Optimise continuous learning and work together to promote innovation and resident focussed service changes.

¹¹Allocation of apartments to individuals and couples is usually managed by extra care housing providers to try to ensure that there is a balance of people with different levels of need; some with few needs ranging to others with higher levels of need.

3) *Work across organisations to deliver the shared vision of extra care housing*

- Continue with person centred approaches; work with social work staff to plan for emotional / wellbeing support as well as physical care needs; consider different job roles.
- Provide strong leadership, develop joint teams as far as possible by reducing boundaries between staff groups and maximise opportunities for shared development e.g. joint training etc.
- Work as a team to create a culture where relationships, social groups and individuals can thrive.
- Raise awareness of how to interact with, communicate with and support people with dementia, their families, and volunteers.
- Consider how to maximise the spatial environment to support social interaction between extra care community members, to manage risks and to minimising behaviours that challenge.
- Develop a shared quality and operational excellence model that includes residents, partners and other service providers.

The recommendations focus on different stages of the developing the vision and commissioning an extra care housing scheme, identifying how the vision will be realised as the transition is made from contract to operational delivery, and operating the extra care housing scheme to deliver the vision. Viewpoints 92 and 93 (the second and third papers in this series) will return to the policy and practice recommendations. They are not intended to be exhaustive, rather they are intended to stimulate high level discussion on whether extra care housing should or could reflect the findings of this research.

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Note

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

About the author

Dr Katey Twyford has over 30 years of experience of developing and implementing business, research and quality strategies within organisations that operate in complex stakeholder and regulatory environments. A key focus has been to support organisations to change and make continuous improvements in performance and customer service. She has just completed a Doctoral Research study in the possibilities and practicalities of people living with dementia in extra care housing. She is a research associate at the Oakland Institute for Business Research and Education and the Centre for Loneliness Studies at the University of Sheffield, and an associate consultant at the Housing Learning and Improvement Network.

About the Housing LIN

The Housing LIN is a sophisticated network bringing together over 40,000 housing, health and social care professionals in England and Wales to exemplify innovative housing solutions for an ageing population. Recognised by government and industry as a leading 'knowledge hub' on specialist housing, our online and regional networked activities:

- connect people, ideas and resources to inform and improve the range of housing choices that enable older and disabled people to live independently
- provide intelligence on latest funding, research, policy and practice developments, and
- raise the profile of specialist housing with developers, commissioners and providers to plan, design and deliver aspirational housing for an ageing population.

To view other examples of housing and dementia, visit the Housing LIN's dedicated 'Focus on Dementia' pages at: <https://www.housinglin.org.uk/Topics/browse/HousingandDementia/>

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