



Extra Care Housing – a Focus on Dementia

Paper 2: The social world of extra care housing – encouraging an inclusive community for everyone

This is the second 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 how extra care housing operates as a social world and how people with dementia can be helped or hindered to be part of the extra care housing community.

The first viewpoint gave insight into when extra care housing is an appropriate choice for someone with dementia, and what factors might trigger someone living with dementia in extra care to move out.

The third and final viewpoint reviews how 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.

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Introduction and key messages

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). This is the second 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.

The first Viewpoint gave insight into when extra care housing is an appropriate choice for someone with dementia, and what factors might trigger someone living with dementia in extra care to move out. This can be accessed at:

<https://www.housinglin.org.uk/Topics/type/Moving-in-and-out-of-extra-care-housing/>

This second paper offers a viewpoint on how extra care housing operates as a social world and how people with dementia can be helped or hindered to be part of the extra care community.

The third and final paper reviews how 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 housing 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

This research found that people with dementia can and do live well in extra care housing, but that it may not be appropriate for everyone. The first Viewpoint explored when it might be appropriate to consider a move to extra care housing and what might trigger a move out of extra care housing. One of the important aspects of moving into extra care housing is being able to develop relationships. An important factor in developing new friendships or relationships was having the right culture with a commitment from all those living and working in extra care housing to make living there a positive experience.

The three questions were asked during the research:

- What is extra care, 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?

Many of the discussions focussed on the ability of residents to take part in community life and the role of staff in providing both formal and informal support to do so. The concept of extra housing care as a social world emerged.

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.

Social worlds within extra care housing

The concept of extra care housing as a 'social world' can help understand how individuals and groups of extra care housing residents experience living in extra care housing, and how they make sense of their place within the extra care housing world. Each of the extra care housing schemes in the research was defined as a social world with a multitude of groups that appeared and disappeared, each with their own shared outlooks and perspectives.

Whilst social worlds are primarily positive, bringing together people with shared interests, there was recognition that some people could be marginalised. The importance of individuals being able to act independently, make their own choices, and reciprocate in relationships with others was explored. It was noted that some individuals with dementia were excluded from groups where this was not possible, which sometimes led to negative relationships with others, including those people in a group that was often described as the 'in crowd'. The culture and behaviour of the 'in-crowd' was explored and it was recognised that people's behaviour could be affected by their own concerns and fears about moving from being active to being frail (for further reading on concepts of an active third age and a frail fourth age see Gilleard & Higgs, 2010). The findings of the research suggest that there may be an unrecognised social world made up of those in their third age, whose members were becoming less active and possibly fearful of what may lie ahead in the fourth age. One manager talked about how residents might be frightened of what lies ahead when they said:

"It's frightening, because they are seeing it [dementia]. Whereas someone who lives in the community may take it on board a little bit better because they don't see it day in day out... If they think that's going to happen to them, they want to block it away don't they?"

The importance of support from staff to help individuals to join and be accepted in social groups was recognised, and a dedicated role that could work across current staff groups was suggested. The current economic climate and resource limitations were recognised as some of the factors that precluded such a dedicated staff support role being developed within extra care housing care.

How do social worlds in extra care housing operate?

Organisational culture was described as central to how extra care housing operated. Culture and professional judgement affected how tools such as allocation panels, allocation agreements, tenancy agreements and resident meetings were used by staff and managers to ensure individuals were appropriately admitted to the extra care housing social world. They were also used to mediate tensions and seek harmony between the different groups. Organisational culture was shown to affect connections and relationships between staff and resident social worlds, and appeared to influence how flexible staff were in supporting residents to be part of the extra care housing community.

The complex interaction between organisational structure, social worlds and the spatial design of the scheme was explored. Flexible use of communal space can encourage a wide range of formal and informal groups to develop, and it was noted that visible appropriation of space lent power to groups of people using the space. The role of staff in mediating membership of groups and the use of space was not clear, and could usefully be addressed through the development of a shared vision for extra care housing as described in the first Viewpoint in this series.

Using social worlds theory to explore the issues raised by participants in the research highlighted that the nature and membership of groups can impact on the experience of people in extra care, especially those who may be living with dementia. It provided insight into the way that individuals navigate the boundaries between the private space in their own home and the social world of the extra care community. Although some people may choose to be alone in their own home, participants said that having access to relevant groups⁴ was important if the needs of extra care residents were to be met. One resident who lived with a partner with dementia said:

“A lot of the time we are happy [in their own apartment] but I do like friends when I come down, and as I have said, we have experienced nothing but kindness when we have come down occasionally, you know...”

Another resident reflected on how supportive they are to each other when they said:

“There is community spirit. I think we support one another as best we can. And I think we identify people with needs, and we’ve had people in here with Alzheimer’s who have needed a lot of care and support, and they’re not, sort of, segregated. They are part of it, aren’t they?”

An essential element of the extra care housing model described in the first Viewpoint is to have a well-developed community, determined in part by where the scheme is located, and in part by whether there were enough activities or groups of interest and whether those groups existed in harmony with each other.

In talking about the importance of location one manager described the benefits of being centrally located:

“The café is just unbelievably superb. Not because of the café particularly, but because it is such a community resource. In that they get school children in, they get workmen in, they get people coming in just for a coffee or whatever. It is slap-bang in the middle of town, and if you go in at lunchtime, it is heart-warming really to see somebody who is a 15-year-old at school coming in and just saying hello to their grandma who is across the other side with her friends. And that for me is just fantastic, but we are very lucky to have that right in the very middle of town.”

A well-located environment is not sufficient on its own. Although there were really positive examples of support and inclusion, there were also examples of where it wasn’t happening quite so well. One manager described how some people can be alienated when they said:

“It had been reported that the residents had been quite negative towards some other people, and not wanting to speak to them, not wanting to interact with them, excluding them from certain areas...”

The journey from making a decision to move to extra care housing to becoming part of the extra care housing community is shown in *Figure 1* below. At each stage the support of other people in providing advice, making decisions, and providing practical help to settle into a new home, a new community and new friendship groups can be crucial.

⁴ Participants did not use the terminology of social worlds theory, rather they used commonly understood terms such as ‘groups’ or ‘cliques’ or ‘clubs’ to describe the different social worlds that exist in extra care.

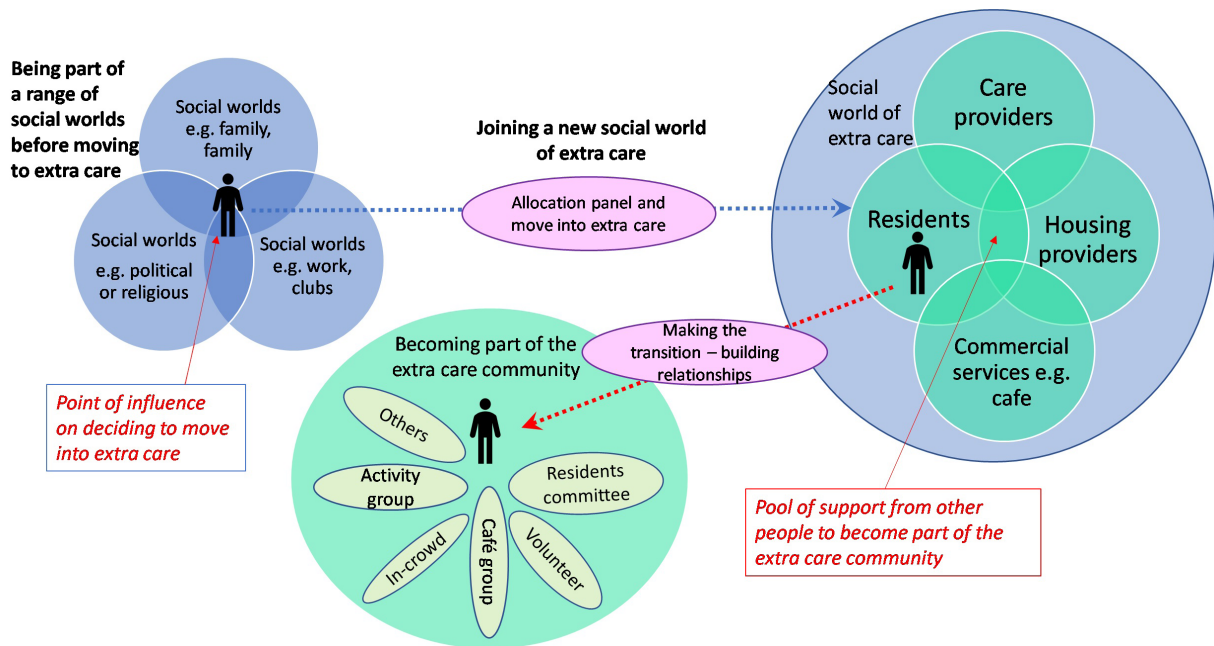


Figure 1: Being a member of social worlds and social groups

In this research, the nature and availability of social groups and activities in the extra care housing social world appeared to be influenced not only by the culture in the scheme, but also by the commitment and availability of people to support or sustain them. As one resident said:

“I’ve stopped going to Craft because it’s not what I want to do because I don’t want to sit and colour... So, the people who are more able are expected to be a volunteer and support the people... rather than it being a craft thing. If we want to do any sewing for example, we’d have to do it ourselves.”

There were many examples in the research, such as a cinema club in one scheme, where involvement in activities worked well. Positive models of engagement in formal and informal groups and in activities to combat loneliness can be seen in other schemes as well; see, for example, the Housing LIN guest blogs on the role of Community Circles (Wilton, 2018) and creating space for men in extra care housing (Spellman, 2018). The success of activities can depend upon the availability of both volunteers and formal organisational support.

Organisational support from extra care housing partners is dependent on their approach to service delivery and operational constraints. In this research extra care housing was delivered by partnerships of organisations and a shared approach to operational delivery across extra care housing partners was considered helpful in creating a social world with a well-developed community supporting individuals to live well.

A call to action – developing an inclusive extra care housing community



The first paper in this series, Viewpoint 91, noted that participants in the research appreciated that staff and residents were often willing to go the extra mile to make sure people were able to live well together in extra care. It set out a call to action to keep residents at the heart of extra care housing.

Three main issues were identified in relation to how an effective extra care housing service could be delivered: first, the availability of support staff; second, effective use of space by individuals and groups helped by having a well-designed environment; and third, managing quality across extra care partnerships.

This Viewpoint has considered how groups form, how they can be affected by the use of the spatial environment in an extra care housing scheme, and how staff support is important in helping someone to develop relationships with others.

Policy and practice recommendations for extra care housing commissioners, developers and providers were set out in Viewpoint 91, and are repeated in Box 1 below. They are not intended to be exhaustive, rather they are intended to stimulate high level discussion on how best extra care housing can support people with dementia to live well. Let's start to use our understanding of social worlds to help shape discussions between commissioners, developer and extra care housing providers about how it can provide an inclusive community for people living both with and without dementia.

Box 1: 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 allocation⁵ 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.

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.

⁵ Allocation 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.

- 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.

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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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