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# **Can Extra Care Housing support the changing needs of older people living with dementia?**

Corresponding Author:

Simon Chester Evans, Association for Dementia Studies, University of Worcester, UK  
simon.evans@worc.ac.uk

Co-authors:

Teresa Atkinson, Association for Dementia Studies, University of Worcester, UK

Ailsa Cameron, School for Policy Studies, University of Bristol, UK

Eleanor K Johnson, School for Policy Studies, University of Bristol, UK

Randall Smith, School for Policy Studies, University of Bristol, UK

Robin Darton, Personal Social Services Research Unit, University of Kent, UK

Jeremy Porteus, Housing Learning and Improvement Network, UK

Liz Lloyd, School for Policy Studies, University of Bristol, UK

## **Abstract**

With over two thirds of people with dementia living in the community and one third of those living alone, it is important to consider the future housing needs of this population, particularly as symptoms of cognitive impairment increase. Policy in England has focused on enabling people living with dementia to remain in their own homes for as long as possible, often with the support of a family carer. However, many people struggle to maintain an acceptable quality of life in their own homes as their dementia advances, often due to the design limitations of mainstream housing and the challenge of finding specialist domiciliary care that is affordable and of sufficient quality. Extra care housing (ECH) offers a model that aims to support older people living in their own apartments, while also offering specialist person-centred care as and when it is needed. This paper reports on a longitudinal project that explored how ECH can respond to the changing social care needs of residents, including those living with dementia. Participants included residents and staff from four ECH schemes, one of which was a specialist dementia scheme, in two regions of England. Interviews were carried with 51 residents across 4 rounds at 5 month intervals between October 2015 and

June 2017. Interviews were also carried out with 7 managers, 20 care staff and 2 local authority commissioners of housing for older people. Key factors included person-centred care and support, flexible commissioning and staffing, appropriate design of the environment and suitable location of the scheme within the wider community. The challenge of delivering services that addresses these issues during a period of reduced public spending is acknowledged. Further research is suggested to compare different approaches to supporting people with dementia, including integrated and separated accommodation, and different stages of dementia.

## **Background**

Over two-thirds of people with dementia live in the community, one-third of whom live on their own (Alzheimer's Society, 2013), making it important to consider the future housing needs of this population. In England, the Dementia Strategy (Department of Health, 2009) and the Prime Minister's Challenge on Dementia (Department of Health 2012; 2015) provide the context for policy, which has focused on enabling people living with dementia to remain in their own homes for as long as possible. This is also the preferred option of most older people, particularly in contrast to residential care (Gott et al., 2004). However, there is little reference to supported housing in general and ECH in particular in UK Government policy. Many people struggle to maintain an acceptable quality of life in their own homes as their dementia advances, often due to the design limitations of mainstream housing and the challenge of finding affordable domiciliary care. In this context extra care housing (ECH) offers a model that aims to support older people living in their own accommodation, while also providing person-centred care. ECH emerged in the UK during the 1980s and has gradually grown in popularity, with approximately 1600 schemes available by 2016 (LaingBuisson, 2016). Initial growth in the social housing sector (mainly housing associations and local authorities) was driven by the availability of substantial Government funding. However, this was substantially reduced after 2010, leading to a slowing down in new build and subsequently the emergence of a range of funding models, including increased provision of apartments for private purchase, drawing on capital finance through the sale of a family home or equity release (Housing LIN, 2014). Over this period the ECH approach has

evolved into many forms, with many different names (Howe et al., 2013). However, the three key common characteristics remain a focus on supporting 'independent living' in self-contained accommodation for rent, shared ownership or sale; care that is available 24 hours a day; and access to a range of communal amenities such as a shop, restaurant and laundrette (Evans et al., 2017). Not everyone living in ECH receives care, and any care that is provided has to be paid for privately or through adult social care.

ECH has seen considerable innovation in the design of the built environment to support people with dementia (Torrington, 2006; Utton, 2009; Alzheimer's Society, 2017; Park and Porteus, 2018). The environment can present challenges for people living with cognitive impairment, sometimes exacerbating their symptoms, but adaptations to the environment can have a number of positive impacts including assisting with wayfinding and reducing the need for support (Jackson and Kochtitzky, 2001; Ebersole *et al.*, 2004; van Hoof and Kort, 2009; Hadjri *et al.*, 2012).

The supported living environment provided by ECH is associated with improvements in self-reported limitations and cognition (Holland *et al.*, 2016). We also know that independence and control over personal space are important factors in the concept of 'ageing in place' (Ahn, Kwon and Kang, 2017). However, the realities of supporting residents as their dementia advances has presented many providers with significant challenges in offering a 'home for life'. Questions have also been raised about the extent to which ECH can continue to provide an alternative to residential care (Darton *et al.* 2012).

Studies indicate high levels of satisfaction among residents of ECH and confirm its potential to promote a good quality of life for people living with dementia (Evans and Means, 2006), not least compared with other long-term care settings (Reimer *et al.*, 2004), although there is some evidence of problems with access to social care (Phillips *et al.*, 2013).

Evans *et al.* (2007) suggested three factors that enable residents with dementia to remain independent: freedom to come and go, opportunities for self-care, and the choice of how to spend their time. With the advantage of specialist support such as the 'locksmith', whose role is to 'focus on unlocking the potential and to enable individual residents to enjoy an enriched lifestyle' (Brooker *et al.* 2011, p 2), ECH can maximise dignity and self-reliance for

residents with dementia. However, specialist services of this nature are not provided consistently across the sector and often depend on the approach taken by particular providers. Evans *et al.* (2007) also identified three specific challenges to supporting residents with dementia: access to health care, training of staff and the provision of a sufficiently stimulating environment. Further studies have highlighted other potential limitations of ECH, including its ability to support people with more advanced dementia (Evans *et al.*, 2007; King, 2003), the risk of social isolation among some residents with dementia (Evans and Valletly, 2007) and higher levels of frailty (Petch, 2007). It is also important to recognise that the broader health and social care context within which ECH sits has changed dramatically since it first emerged. Smith *et al.* (2017), for example, have drawn attention to some of the complex challenges faced by those commissioning adult social care for residents in ECH, highlighting the central importance of reduced funding, meeting only higher eligibility criteria, increasing costs as a result of demographic change and the introduction of the national living wage (a mandatory pay rate for workers aged 25 and over).

While the evidence base for the benefits of ECH has slowly grown, including its potential to save NHS and social care costs (Holland, 2015), there is little research into how it can support people with advanced dementia, and the advantages of different models and designs of ECH for people living with dementia (Dutton, 2010). Previous studies have also identified stigma and prejudice as possible barriers to social interaction for residents with dementia (Evans *et al.*, 2007). It is well established that social isolation can impact on quality of life for older people in general (Bowling and Iliffe, 2011) and for people with dementia in particular (Cohen-Mansfield, 2007). Other possible impacts of dementia-related stigma for individuals are low self-esteem, feelings of shame and dehumanisation (Evans, 2018).

### **Aims of the paper**

This paper reports on a longitudinal project that explored how ECH can respond to the changing social care needs of residents, including those living with dementia. The overarching aim was to investigate how residents in ECH schemes make decisions about the changing nature of their care needs and how they negotiate these with care providers. In this paper we predominantly focus on the views of residents and staff at the specialist

dementia scheme (Site C). We also draw to a lesser extent on data from the other three schemes, where some but not all residents were living with dementia..

## **Research Methods**

Four ECH schemes were recruited to the study from two localities: a unitary authority, experiencing pressure on land with plans for large scale investment in ECH (Area 1), and a county council, two tier authority which, at the time of the research, was struggling to fill places designated for local authority supported people (Area 2). Each scheme was visited on four occasions at 5 month intervals over a 20 month period. Data collection included semi-structured interviews (with 51 residents, 7 managers, 20 care staff and 2 commissioners of housing with care), documentary analysis and unstructured observations. One scheme (Site C) provided specialist support to people with dementia. This was a new build ECH facility, which provided accommodation for people who had previously lived in a nearby care home for residents with mixed care needs. Residents of this care home who wished to move to the new dementia specialist ECH facility could do so. A majority, but not all, of people living in this scheme had dementia. Only residents who were assessed as having capacity to consent were included in the study. The process consent method (Dewing, 2007) was adopted to assess capacity at each stage of the research.

A total of 51 residents took part in the study through 164 interviews across the four rounds as shown in Table 1.

*Table 1 here*

Managers at each setting were interviewed twice, on the first and last visits to each scheme. Over the course of the study, there was a change in manager at three of the sites. Interviews were also conducted with a total of 20 care workers across the 5 schemes. From a total of 11 residents who participated at the specialist dementia scheme, only 2 participants completed all four waves of interviews. Following the first wave of interviews, one resident passed away and one withdrew. In wave two, a further 7 residents were recruited, 4 of whom only completed wave 2, with the remaining 3 residents completing all subsequent waves of interviews. Finally, we carried out a total of 4 interviews with commissioners who covered each of the two regions, one each at the beginning and the end

of the study. These are officers from the local authority with responsibility for implementing strategies for housing and funding ECH services for some residents.

Interviews were audio recorded, transcribed and subject to thematic analysis using specialist software. Two members of the research team read a sample of transcripts to develop a coding framework, which incorporated a priori codes drawn from the literature, supplemented with themes arising inductively. Thereafter one member of the research team read and coded the remaining transcripts. The framework was reviewed and adjusted both after each new round of data collection and during coding. Researcher notes and documents were analysed to provide context. There were specific challenges associated with including residents with dementia in the study, particularly at the specialist scheme. These included a relatively high drop-out rate over the four phases of interviews and the limited number who had capacity to consent to participate. Good practice was followed including spending time getting to know participants, giving plenty of time for responses and offering regular breaks. Approval for the research was granted by the National Social Care Research Ethics Committee (reference 15/IEC08/0047).

## **Findings**

The findings are presented here under five main themes:

- Independence and control
- The built environment and location
- Awareness and stigma
- Opportunities for social interaction
- Challenges for staff

Quotations are labelled using the following system: S stands for site; A,B,C,D identifies individual sites; R stands for Resident; CM stands for care manager; CW stands for care worker.

### **Independence and Control**

Promoting independence is often mentioned as one of the key benefits of ECH and is a feature that appears to be valued by many residents living at the specialist dementia scheme. For example, one resident said:

*'Well for (a) start off you're still yourself and that's what I like, you know, they're not coming round and saying you've gotta ... they don't, but if you ask them anything you want them to do they'll do it.'* (SCR3)

*'Do you want me to do this? Do you want me to do that? And I say no because for the simple reason at present I'm able to do it but they do pick up things and what have you.'* (SCR3)

However, a truly person-centred approach is required in order to provide appropriate support while still maximising opportunities for independence and control. Some residents at site C gave accounts of the care which they received which appeared to depart from this ideal:

*'They make the bed for me and draw the curtains back and they get my breakfast for me here, not over at the café, and they come in each meal time and then they come in at eight o'clock to get me into my night clothes ready for bed. I don't go to bed at that time but that's my time and I'm sitting watching television by then.'* (SCR1)

Another resident felt that his current living arrangements in the ECH scheme were an insurmountable barrier to independent living:

*'You're tied and limited. If I wanted to have a reasonable life really I would need to leave here so that I could be independent. I could come and go and go to a pub and have a pint or two at night or whatever and just wander back home a short distance. I haven't got it. I haven't got that situation.'* (SCR6)

For some residents the focus on 'promoting independence' was too much of a change compared to the residential care home in which they had previously lived:

*'When I was in the old house, it was residential and we were cared for. Here it's dementia, and it's like living in your own flat, you're independent in your own flat and they have quarter hour slots to look after you. As I say I don't see anybody all day until half past seven when they come and give me a quarter of an hour. Now to me that's no way of looking after people, BUT, that is the system now, it's changed. You see perhaps I ought to move and go somewhere where it's residential I don't know, but I'm a bit too old to be bothered.'* (SCR11)



So, while there was evidence that both staff and residents valued the ethos of independence, this commitment to the aspirations of ECH did not always translate into practice in the dementia specialist scheme.

Staff at all four schemes recognised the aspiration of ECH to support independence. There was an understanding that this was not straightforward and required a person-centred approach, as identified by a care worker at one of the non-specialist schemes:

*'If you've got someone with dementia yeah, we will promote independence and I think that's what we need to focus to promote it, but it's not that "Oh if she's here let's expect her to be independent" because that's not how it works. They sometimes can do only small things – let them do those small things, if they cannot do the big ones help them and let's see how we go'. (SACW1)*

### **The built environment and location**

The design of the built environment at the dementia specialist scheme appeared to be a significant factor in the day to day experiences of residents. One resident suggested that the environment provided security:

*'Yes. I feel safe. I don't feel anybody knocking on the door like, and so strangers are there, no. I don't get that. Because my main door I can see from here.'* (SCR4)

However, for some residents the environment appeared to contribute to a sense of social isolation, both within the scheme and in relation to with the wider community:

*'Even the building makes it, you know lonely I think. Say this place now, I come through that door, that's the main entrance and all I have here to go is just this. That's supposed to be kitchen isn't it, kitchen, living room, one bedroom. I think I lived (place name), it was two bedroom. It wasn't this upstairs, it was more a flat. You could have at least two bedrooms so when I have my relatives come to see me, my children...'* (SCR4)

*'You've got to go out of the building and across up into there on the local roads and make your way here, there and anywhere you can get to buy. You can't go to the shops or nothing. They haven't got any!'* (SCR6)

As the previous quote demonstrates, location is important when considering a site for ECH. The responses of some residents suggest that greater self-reliance can only be achieved if

multiple aspects of the ECH environment are taken into account. The location of a scheme, for example, can restrict opportunities for autonomous activity:

*'Yes, and try to walk up to the local Co-Op or something like that, but I don't know how far it is. Well, it's not far up the road. I've been in the car and seen it but I don't just know quite how long it would take me so I'm a bit nervous about risking going up there.'* (SCR1)

The background to the specialist dementia scheme is important to consider. Many, but not all, of the residents came from a nearby residential care home, which the scheme was replacing. This meant that they were dealing with a sudden change of environment in terms of both physical design and care provision. It is likely that this impacted on their experience of the ECH environment and may have exacerbated disorientation.

Understanding the need for dementia-friendly design to be incorporated into integrated schemes may require some discussion to overcome initial resistance. Whilst many of the features of dementia friendly design underpin the principles of good design for *everyone*, some of the dementia friendly elements, such as signage, colour contrast, etc, may cause tension with other residents. This was reflected in a comment made by one local authority commissioner that their plans to incorporate dementia-friendly features in a mixed tenure new build were resisted:

*'But also, we have compromised on stuff. So, for example we wanted it to look more dementia friendly than perhaps was acceptable to private buyers coming in. So, we have had to compromise on stuff like that to try and mitigate some of that risk, which is fine; we accept that that is a competitive dialogue process, we have to accept that they are the experts.'* (Commissioner for Area 1 – sites A & B)

### **Dementia awareness and stigma**

Our findings also suggest that despite increasing awareness of dementia, there is still considerable stigma and prejudice among other residents. There was some evidence of a lack of understanding about dementia on the part of residents across all four schemes that took part in the study. At one non-specialist scheme for example, a resident said:

*'When I first moved in here three and a half years ago I didn't even know what it was about. I didn't even know there were dementia people here. I must have taken me a good year to understand why they were here. And then ever since then I've been asking questions about them as well. I still don't understand. So, it's very ... it's difficult*

*living here, especially when you haven't got dementia yourself because some of those dementia people tell you off and they're very aggressive with it.'* (SAR9)

The mix of residents and attitudes towards people living with dementia also appeared to have an impact on opportunities for residents to interact socially. There was a perception at two of the non-specialist schemes that living alongside people with dementia restricted the opportunities for other residents to take part in activities they might enjoy:

*'There are activities here which I am not interested in. They have a café downstairs where the dementia people have their meal, and they play bingo every Saturday. They do a racing sort of game every now and then but I'm not interested in those sort of things because the dementia people go to them and it is pointless going to any activity with them when they ignore you.'* (SAR9)

*'I'd like a workshop. I used to do a lot of model making, wooden.....I don't think there would be the following actually because the residents are a different mix to what the villages are. The residents here are predominantly dementia so you can't have activities like that with them.'* (SDR12)

At the specialist scheme, there was evidence of prejudice on the part of the small minority of residents who didn't have dementia.

*Well yes and we all mixed up better than here, I mean I can't go and sit down there, there's nobody to talk to. You can't talk to demented folks. I mean it's a load of rubbish.* (SCR11)

While this illustrates how stigma can be a barrier to integrating people with and without dementia in extra care housing, it also highlights some of the specific challenges that can be raised by the re-provision of residential care as a dementia specialist scheme.

### **Opportunities for social interaction**

The ECH model can also offer valuable opportunities for social interaction and participation in activities, as indicated by two residents at the specialist dementia scheme.

*'I've got more social contact because I've got all these people around me now in the same boat as me so to speak.'* (SCR1)

*'Yes, we play dominoes and bingo and [pause] I'm doing some tapestry at the moment and knitting squares for a blanket. Yes, yeah. And that was one of the things I really wanted to come for, to join in with the activities.'* (SCR1)

One resident at this scheme described how a lack of activities discouraged her from spending time in communal spaces where she might meet other people: 'Most days I go down [to the lounge] but I don't spend a long time. Because I don't think there's much going on, they don't have much activity.' (SCR4).

Another resident expressed a desire for more opportunities to do things away from the scheme:

*'I miss going out to play some sort of a sporting game or go out on trips. You know if they would form like a club where they can take people out on a coach trip or something. That would be interesting because you can ... I don't mind paying for a coach trip to take you places.'* (SCR4)

Some residents at the specialist dementia scheme appeared to be lonely, although it is also important to distinguish this from being alone and to recognise that some residents valued the peace and quiet.

*'I used to go and meet up with four friends of a Wednesday and have a coffee and hour in town when I was capable, and I used to have - that's with four of my friends - and then another couple of my neighbours we used to have a taxi once or twice a week and go into town regularly and do our shopping. And I miss that.'* (SCR1)

*'No, I don't think I do [have things in common with the other residents here], probably don't have anything in common [laughs], I don't know. Because I'm sort of lonely up here, sort of by myself most of the time and err ... Yes, I don't seem to have any visitors. Yes, I couldn't cope, I wouldn't say I wouldn't but I couldn't cope with a lot of people coming in and out.'* (SCR4)

### **Issues and challenges for staff**

Interviews with scheme managers identified a range of challenges that staff experience in providing appropriate support for residents with dementia.

A manager at the specialist dementia scheme spoke about her desire to support residents for as long as possible and mentioned that no one had been required to move on due to their needs becoming greater than they could manage. She acknowledged that, while in theory ECH provides a 'home for life', the fact that residents were all living with dementia posed additional challenges compared with non-specialist schemes, and some residents

would end up needing 24-hour care elsewhere. In other schemes, managers described situations where they were no longer able to support residents due to their dementia.

*'She just could not settle here at all and we got to the stage where staff were going out of the building looking for her and then we'd be calling family day and night. We've called the police and they even had the police helicopter up looking for her one night because we couldn't find her. So we've tried all ways, we've tried the assisted technology on the door ... just didn't work, nothing worked. It just wasn't safe for her anymore. (SBCM)*

Another resident in the same scheme, who was perceived to be scaring other residents by walking within the scheme at night, was successfully supported by the use of assistive technology that automatically alerted staff.

Staffing arrangements and systems were also felt to have a significant bearing on the extent to which residents with dementia could be supported. Managers at the specialist scheme acknowledged the value of person-centred care and support for residents living with dementia.

*'Extra care for people living with dementia is a great concept. It's a great way to keep people living independently for that little bit longer, if possible. However, it really does come with its challenges to be able to be flexible like we need to be to support people with dementia. I will say that the team, the care and support workers, are really good in that they know their clients so well. If they do go to somebody who that particular day doesn't want to go to bed, they're very good at working together to say, 'Gertrude is looking like she wants to go to bed in the communal room. Let's swap this with Gertrude. Let's move Isabella to her time.' (SCCM)*

The same manager also suggested that current approaches to managing care across the sector based on fixed rotas present challenges for providing person-centred care and support. However, commissioning arrangements that include some 'floating' hours can be very effective in overcoming such restrictions.

*'We recently had a lady move in and we noticed a couple of mornings we'd gone in, she'd fallen in the early hours of the morning. We had some floating time, so we put in a welfare check three hours before she was due to get up, so we could capture her or try and discover what the pattern is, what's the trigger, what's happening. It is constantly always evolving.' (SCCM)*

This manager also recognised the importance of continuity of care to residents with dementia.

*'When people have got dementia, having a face that comes in they don't recognise and then doesn't know their care routine, that will probably cause them more disruption to their routines and could cause some behaviours. I don't think that's good management of people. So, if I have to work a care shift myself, then so be it. My deputy and I do cover a lot if we have to, but that's what we normally do so I've never used agency since I've been here'. (SCCM)*

At the non-specialist schemes, staff appeared to recognise the potential complexities of living with dementia. A care worker at Site B described how this could impact on her role as a carer:

*"One of my residents that I look after has dementia. She has diabetes as well. It can be quite challenging depending on her mood. I've got to basically, when I work a morning shift, I have to get her up in the morning. I have to ensure that she's having her food which can be quite challenging at times because sometimes she just might not want to or she can kind of go off track with her attention so that can be quite challenging at times getting her to take her medication. And keeping her on track 'cause when she's doing stuff she can have her medicine in her hand for one second and then the next second she'll completely forget what she's doing and she can put things in random places and, so yeah. I would probably say she's one of my most challenging but most enjoyable at the same time if you know what I'm trying to say.' (SBCW2).*

One non-specialist scheme included a 'locksmith', who provided additional support for residents with a range of mental health issues. The manager felt that this a key aspect of the service provided:

*'The aim being that we can continue to support people here for far, far longer than actually they would be either in their own home or possibly in residential care. We've got a few people here who are quite a long way along their path with dementia but actually because of the support that's on site and the fact that they know us well and we've supported them throughout the years, they can continue to stay for far longer than they probably would have done'. (SDCM).*

Managers in non-specialist schemes highlighted the limited information that they might receive about whether a resident has dementia before they move in.

*'The problem is when we get the referrals come in it will... it might say 'suspect' you know ... it might just say 'generic dementia' but then when we talk to family and say "has there been a formal diagnosis?" they'll say "No, no but they have got dementia." So ... and we're not necessarily privy to that information because it's still independent living. We don't have access to medical records.' (SACM)*

The situation was clearer in the specialist dementia scheme (site C), where they received a professional assessment of new residents' cognitive capacity.

The complexities and challenges of supporting residents with dementia can be demanding but can also be addressed by the flexibility of the ECH model. One commissioner described how requests to increase care packages on a temporary or permanent basis are addressed:

*'They request a re-assessment and then we do a re-assessment of their needs and then up the hours accordingly. We also like to be flexible with temporary [changes in care], so one scheme they said, "We just happen to have five people with quite difficult dementia and we need to get some extra staff in temporarily". So we gave them a block of money for a period of about three months to do that.'* (Commissioner for Area 1 – sites A & B)

This approach suggests that ECH has the potential to respond to the care needs of residents living with dementia as they change over time.

## **Discussion**

The findings from this study confirm previous evidence that supporting people with dementia in ECH can be complex and that a person centred approach is required (Evans *et al.*, 2007; Brooker *et al.*, 2011). However, the research reported on in this paper also suggests that while ECH has the potential to respond to the changing care needs of residents living with dementia, and staff and management both indicated a desire to respond to such changes rigid staffing arrangements can present a major challenge to achieving this in practice. This can be due a range of factors including financial pressures and uncertain working terms and conditions for low paid staff. It is also important to note the challenge of providing a 'home for life' for residents with dementia. For some, the organisational response to changing care needs is to initiate a move to another setting. Most residents with dementia valued the ability of the ECH scheme they lived in to encourage independence, and staff also recognised the importance of this to quality of life for residents. This supports previous findings (Evans *et al.*, 2007), but it is important to note that the dementia specialist ECH scheme in our study had been built to replace a residential care home. Some residents found the ECH setting to be a restriction to their autonomy, largely due to the challenges of accessing acquaintances and amenities in the wider community. The design and location of ECH schemes can have a major impact on the

independence of residents, as highlighted in previous research (Torrington, 2006). For example, the design of the specialist dementia care facility posed challenges for access to dining facilities and engaging socially during meal times. The café was located in a separate part of the building which was not linked to the main accommodation and lounge spaces. This necessitated staff being available to escort residents to the dining facility to ensure their safety in transiting the outdoor space, which also led directly onto a main road. The dining facility was small which necessitated small numbers of residents being escorted for different 'sittings' for lunch. Whilst this was potentially beneficial to encourage small groups to sit together and engage in the social aspect of a shared meal, it did pose challenges in requiring some residents to wait for a later time slot for their meal. The limited flexibility of support arrangements can also be seen as a barrier to independence, as evidenced by the resident who was encouraged to prepare for bed long before her preferred bedtime.

Our findings also suggest that ECH can offer opportunities for social interaction and meaningful activity, as found in earlier research (Evans and Vallely, 2007). However, such opportunities were not always equally accessible to all residents and some residents with dementia at the specialist scheme indicated that they felt lonely, which may be linked to the stigma and prejudice that continues to be associated with dementia. The design of the dining space was also shown to be an impediment to spontaneous and independent social interaction in the specialist scheme. Our research suggests that a level of understanding about dementia amongst the residents living within the ECH community is also required in order to help them to understand and co-habit harmoniously with residents living with, or developing, dementia. The need for a culture of care that gives people living with dementia the confidence to access communal spaces and an environment that is sufficiently easy for those with dementia to access and navigate, is particularly important and requires an enhanced level of understanding and training for staff.

Social interaction and meaningful activity can also be maximised by ECH facilities which offer safe and independent access to amenities such as shops, restaurants, pubs, libraries and hairdressers. These were noticeably absent in the dementia specialist facility included in this study. Again, this is particularly important to people living with dementia, who arguably have a greater need to be able to access such facilities in a safe manner and would



benefit from more on-site facilities. Many ECH schemes operate successfully as community hubs which open up the onsite facilities to the wider community. This relies on a successful balance 'between overcoming the sense of intrusion felt by some residents with the opportunities for social contact that others welcomed' (Evans *et al*, 2017, p 29).

Overall, our findings suggest that commissioning and staffing arrangements that allow a person-centred approach are key to supporting people with dementia in a way that maximises quality of life as their needs and preferences change.

We also highlight some of the different challenges that specialist and generic ECH schemes present when supporting people living with dementia. For example, although promoting independence is valued by residents of specialist schemes, it may be more difficult to achieve the balance between independence and providing a safe, supportive environment in this setting than in generic ECH. This is because care and support needs are generally higher, which raises challenges for providing person-centred care, and there are concerns about allowing residents to access outdoor spaces and wider communities. Conversely, it may be easier to provide a dementia-friendly environment, although some aspects of design within the specialist scheme in this study seemed to work against this. Our findings also suggest that residents living with dementia in generic ECH schemes may be at particular risk of exclusion due to stigma and prejudice among other residents. This situation might be exacerbated by the lack of information that generic schemes often have concerning the cognitive status of residents. However, residents in specialist schemes can also feel lonely, largely due to the challenges of accessing the wider community and maintaining friendships beyond the scheme.

## **Limitations**

This paper draws on data from four extra care schemes, one of which was a specialist scheme for people living with dementia. This limits the extent to which some of the findings can be generalised to other settings. However, all four schemes supported residents both with and without dementia. The longitudinal design of the research presented some challenges in collecting the views of those people living with dementia in terms of initial

recruitment to the study and subsequent withdrawal. Similarly, the decision only to include people with capacity to consent is likely to have excluded some residents with dementia from taking part in the research.

## **Conclusion**

The study presented in this paper augments existing evidence for the potential of ECH to support quality of life for people living with dementia as their abilities and preferences change, while also promoting independence. We have identified several factors that are important in achieving this including the provision of person-centred care and support, adaptable commissioning and staffing, suitable activities and facilities, appropriate design of the environment and suitable location of the scheme within the wider community.

Delivering a service that addresses all of these issues is a considerable challenge during a period of financial restrictions, particularly for schemes that rely on public funding, and without a clear national strategy for older people's housing. The relative importance of these factors is likely to differ according to the model of ECH that is adopted. For example, it may be easier to incorporate dementia-friendly design in a specialist scheme than in a non-specialist setting. Further research is required to explore the comparative advantages of different approaches to supporting people with dementia, including integrated and separated accommodation, and at different stages in their dementia.

For ECH to be an effective option for people with dementia, designers, commissioners and care providers need to move beyond providing for a generic population and think more specifically about providing for anyone who has or may develop a cognitive impairment. Previous studies have suggested that developing increased impairment in situ can be less problematic both for the resident (due, for example, to familiarity with their surroundings) and for their neighbours, who will have got to know them before they became increasingly frail (Croucher *et al.* 2007). This, in turn, can help to reduce stigma and isolation. As the prevalence of dementia increases so too must the sector be ready to face the challenges and opportunities that this presents. Having a home, particularly a home for life, is a core

part of any adult aspiration; a basic human need and a basic human right. For people living with dementia, this is even more essential; as dementia progresses, the familiarity of somewhere recognisable as a place of safety, a place of security and a place of comfort is a reassurance that should not be underestimated. The findings reported here suggest that extra care housing can meet this challenge, but only through a truly person-centred approach to the provision of care and support.

Lessons are also drawn about the opportunities and challenges for carrying out research with residents who have dementia. In order to capture the experiences and views of people with a wide range of types of dementia and at different stages of the disease, innovative research needs to be available in addition to verbal interviews, particularly when communication in later stages of dementia becomes a barrier to engagement.

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The Author(s) declare(s) that there is no conflict of interest

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