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What is the 'extra' in Extra Care Housing for people living with dementia?

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[BOX OUT]

Project background

Funder: NIHR School for Social Care Research.

Partners: University of Worcester, Housing 21, Housing & Learning Improvement Network (Housing LIN), Housing and Dementia Research Consortium and Worcestershire County Council.

Advisers: Professor Richard Humphries and people affected by dementia on our advisory group.

[BOX ENDS]

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Key points

- More than 20% of people living in Extra Care Housing (ECH) have dementia and yet little is known about how best to support people to live well with dementia in ECH
- Flexible care provision, a focus on supporting independent living skills, the safety and reassurance provided by staff on-site, social opportunities, and age-friendly living can all provide an “extra” layer of support within ECH
- Commissioning of ECH is a challenge, and provision is hugely diverse. This can mean that the “extra” is not always accessible for all residents living with dementia

- There are many variables that affect access to the “extra” and there is no one-size-fits-all model of ECH. Yet, with the right person in the right housing with the right resources and relationships around them, a person living with dementia can thrive in ECH

[BOX ENDS]

Extra Care Housing (ECH) is a type of specialist housing for older people focussed upon independent living with support. Residents have their own flat or apartment within a larger scheme and a key feature is the on-site provision of flexible care and support that can be planned around each individual resident.

While some people have no care at all, others will have multiple calls per day with a focus on sustaining independence. Schemes vary significantly across the UK, with differences in size, facilities, organisation, and tenures.

For people living with dementia – by which we mean both those with the condition and their family carers - there are different models of ECH provision. Most schemes are integrated living, where those living with dementia live among those without the condition, but some schemes offer specialist provision that is only for people living with dementia. A minority of schemes offer a smaller, separated area within an integrated scheme, where more intensive support for residents living with dementia can be provided.

Over a fifth of residents in ECH have some form of dementia (Barrett 2020) and yet there remain significant gaps in research on how best to support them to live well in this type of housing.

Our research

Stage 1 of our project (Atkinson et al 2021) involved a survey and consultation with people with dementia, family carers and adult social care commissioners. This shaped data generation for stage 2, which entailed interviewing 100 people across eight case study sites in England, including 55 residents with dementia and family carers. The remaining 45 interviewees were a mixture of residents without dementia, staff and managers at schemes, social workers, and adult social care commissioners.

On the basis of these interviews we undertook a thematic analysis, which demonstrated that there are several potential benefits that might be construed to be the “extra” in ECH for people living with dementia. Here, we share the findings of this analysis, quoting some of the interviewees who took part.

The “extra” in Extra Care

A particular benefit of ECH is that provision of care and support can be flexible and focussed around maintaining skills and supporting independence:

I make [my wife’s] bed and I make my bed. It’s one of the things I’ve toyed with: the idea that maybe, in the future, the carer who dresses her would then have to make her bed. But, at the moment, I can do it (John, living with dementia).

Such provision can be particularly helpful for a resident living with dementia whose strengths might change across time. An important benefit of having staff on-site 24 hours a day was a sense of safety and security that families and residents report, echoing findings in previous research (eg, Evans et al 2020):

They’re around if I get any problem at all. All I have got to do is call them” (Denise, living with dementia).

Having staff on-site could provide reassurance that help was rapidly available if needed, thereby reducing a level of anxiety that a person with dementia might experience if they are living on their own. For other people, this meant an extra layer of protection from the outside world:

I have no worries because I know that anyone wanting to come in has to get past the [staff].. so I feel safe (Margaret, living with dementia).

Other benefits of ECH included a sense of ownership over one’s private flat, and the opportunities this could provide to surround oneself with familiar things:

This table for instance, I love, because I can hold onto it, and it doesn’t move, like most other things in life do. So, I just grab hold of this when I feel the need... and feel at home (Mary, living with dementia)

This could support a sense of personhood, security and sustain identity, despite the change in home residence.

Opportunities for social activity were also key; for example, having organised activities on-site, as well as informal opportunities over shared mealtimes or in shared spaces:

Life is a good thing when you help other people, chat with them and have a good laugh, basically (Maureen, living with dementia).

Finally, ECH provided an important opportunity for couples to live together with as much care as they required. This could help couples stay together and support them to continue to provide care for each other whether where one partner had dementia or both:

However life changed, we were going to be capable of independent living and that was very important to both of us (Barbara, spousal carer)

Access to the “extra”

It is important to note that the “extra” is not “extra care” as such, despite the name given to this form of housing. Although many people report the reassurance of 24-hour staff on-site as a key benefit, if a person routinely needs 24-hour support, ECH may no longer be the most suitable place to reside. Frequently getting lost or distressed or wanting to leave the scheme when it is deemed unsafe to do so may indicate against continued residence in ECH.

There are many variables that impact on how well a person with dementia can live in ECH. It can be difficult to familiarise oneself with a new home, and new routines. Evidence suggests that the earlier in their dementia journey that a person moves in, the more likely they are to live well and the longer they are likely to be able to stay.

Resourcing flexible provision is difficult. There are different models of commissioning across the country and some schemes have become increasingly inflexible in their care provision. The result can be care that echoes more traditional domiciliary care, undermining the promised flexible “extra” potentially so valuable for a person with dementia.

If there are too few staff on-site, there is the risk that the privacy of having one’s own flat can turn to loneliness, particularly if support or

prompting is required to access social opportunities. Family can help to counteract this risk by continuing to provide informal care.

But there is the additional risk that staff and other residents will view dementia as stigmatising, further isolating a resident whose symptoms are advancing. Access to specialist social support in the form of a key link worker or activities coordinator, or external day centre provision, could provide an extra layer of help and stimulation that extends a person's capacity to live well in ECH. Yet, such opportunities are inconsistent across ECH provision.

So what is the “extra”?

The “extra” is the potential benefit that enables a person to continue to live as independently as they so wish. “Potential” is a key qualification because, such is the diversity both of ECH provision and of people living with dementia themselves, accessing the “extra” depends on multiple variables coming together in the right way.

What that “extra” is, and whether it is accessible, will vary by person, scheme and wider circumstances of support. For example, for someone with mild symptoms, it might be the sense of ownership they have over their flat, and the reassurance for them and their family that they can access care when they need it.

For someone with more advanced symptoms of dementia, on the other hand, it might be a combination of planned care calls that help with activities of daily living, as well as the member of staff in the corridor who can help signpost to the nearest bathroom or remind them of an activity in the lounge.

It is difficult to say just one thing that is the “extra” because it is a combination of factors that must be balanced around the individual to promote their strengths and support their needs to optimise the benefit of ECH. There is no one size fits all. Yet the right person in the right scheme with the right resources and relationships around them can thrive.

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