

Key Insights

Extra Care Housing for people living with dementia: A booklet for adult social care commissioners & professionals



FUNDED BY

NIHR | National Institute for
Health and Care Research



What is Extra Care Housing?

Extra Care Housing (ECH) is a type of specialist housing designed to support independent living.

Each resident owns, rents, or leases their own private flat or apartment within a larger scheme.

There is care and support available onsite if, and when, a person needs it. This is flexible and can be increased or decreased over time as required.

Some residents won't have any care at all, whilst others might have multiple care calls per day to manage their daily life.

ECH often has shared communal spaces, facilities and activities. These will vary between different schemes, with larger schemes often having more facilities.

ECH can also be known by other terms, such as housing with care, or housing with care and support, assisted living, or supported living. For more info, visit the www.housinglin.org.uk.

"It's the best thing, having your kitchen come dinette. Then you got your bathroom and your toilet, and your bedroom.... I love it, it's my best move"

Janet, resident living with dementia





“[ECH is] independent living, within a community and with opportunities for people to take part and be as much a part of that community as they want to be”

Staff member, ECH provider

Different models of Extra Care Housing for people living with dementia

There are different models of ECH for people living with dementia.

The majority of schemes are **integrated** where people with and without dementia live alongside each other. These vary in size, but can be very large (up to 300+ flats). Larger schemes often have more facilities onsite and provide economy of scale.

Sometimes a large scheme will have a **separate** area where people living with dementia live. This does not mean that residents with dementia *have* to live in this area, but it can have more focussed staff support.

Other schemes are **dementia specialist** and only have residents living with dementia. These are usually smaller and have a higher number of staff-to-residents onsite, so can provide more focussed support as symptoms advance.



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

Adult social care commissioner

Pros & cons of different models of Extra Care Housing for people living with dementia

Integrated Schemes

Pros:

Schemes are often larger, with more facilities and offer economy of scale.

Larger schemes have more residents and therefore provide residents with more choice about who to spend time with.

Other residents can provide support and interaction with people living with dementia.

Integrated are the most common model and therefore people have more choice about where they can live.

Cons:

Larger schemes can be disorientating and difficult to navigate without support.

Other residents can stigmatise people living with dementia and may exclude, isolate or complain frequently about residents with dementia.

Staff may not have had specialist training for working with people living with dementia.

There may be lower staff to resident ratios and therefore, less care and support is available. This can leave a resident with more advanced dementia isolated and they can become lonely and/or distressed. In turn, this can lead to worsening symptoms of dementia, which might trigger moving on from ECH.



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

Social worker

Separated Schemes

Pros:

Having a focussed area for people living with dementia can concentrate staff support and provide a smaller area for a new resident to familiarise themselves with.

A separated area within a larger integrated scheme can still offer opportunities for people to mix with a community who are not living with dementia.

Cons:

Can create an “us” and “them” culture.

Residents can be subjected to stigma based on their area of living.

NB. Not all people will receive a diagnosis before moving to the scheme and some people with dementia will not be living in the separated area. Moving flats or apartments is usually not in a person’s best interests.

If you’ve got an [integrated] scheme, then that’s got advantages because people are all different and they’re all chatting... Whereas if it’s all people with dementia, that may be more artificial than living in a mixed population”

Activities coordinator, specialist scheme

Specialist Schemes

Pros:

The specialist support and ethos of the scheme can mean that residents are better stimulated and supported as their dementia advances.

Some people living with dementia find specialist provision appealing as they know everyone is “in the same boat”.

Specialist schemes can be more tolerant of symptoms of dementia, such as confusion, disorientation and walking with purpose.

Specialist schemes are usually smaller and have higher staff-to-resident ratios.

Cons:

May still be stigma from other residents.

Residents living with more advanced dementia might dominate the staff time and those living with mild-moderate symptoms might not get the stimulation required from activities.

Can be harder to fill vacant flats with people with a suitable level of care need.

Managing people wanting to exit the building can be difficult.



“If there’s a problem, there’s staff close by, really it makes a massive difference”

John, family carer

What are the benefits for a person living with dementia in extra care housing?

1. Flexible care and support available onsite to maintain independent living

Staff can provide care and support to support residents to maintain levels of independence where possible. The amount of care and support can be changed as needed over time. For a person with dementia whose needs may fluctuate, flexible provision must be provided.

2. Onsite staff provide a sense of safety and security for residents and their families

Having staff onsite provides a sense of reassurance, safety and security to residents and family members. This reassurance can sustain family members in their caring role and offer a level of safeguarding unavailable in private accommodation.

3. Age-friendly design and convenient living

The best ECH schemes can meet a person’s housing needs by providing properties that include aspects of age-friendly design (e.g. wide doorways for mobility aids) and dementia-friendly design (e.g. line of sight from living room to toilet, clear signposting and appropriate use of landmarks).

As properties are managed by an organisation, residents don’t have to worry about household or garden maintenance, making them a convenient location for people to age in place.

For more on dementia-friendly design, visit the www.housinglin.org.uk.

4. Opportunities for privacy and social interaction

Living in a flat or apartment within ECH offers the resident the opportunity for privacy and to spend time alone. However, living in ECH can also provide opportunities for informal social interaction with neighbours, and organised social activities.

Activities can be organised by an onsite activity coordinator or community development worker, or be delivered by external organisations coming into the scheme.

5. Flats are available for both single people and couples

ECH can support couples to age together in place. Having staff onsite can enable couples to support each other for longer, safe in the knowledge that extra help is available if, and when needed.

6. Ownership and identity

For a resident living with dementia, having their own flat or apartment can be an important. Being surrounded by familiar possessions in one's private space can be valuable for a sense of identity, belonging and can support a person to live well with dementia.



“To me it simply means that I have 24-hour backup, and someone comes to see me a couple of times a day and they do a little bit of washing up”

William, resident living with dementia

A note on the benefits

All benefits are theoretical. Not all ECH schemes will provide such benefits for people living with dementia. Whether a person is able to maximise the potential benefit that ECH can provide depends on a variety of factors that might include the individual's personality and biography, levels of family support, the culture of care, staff resourcing, environmental design, activity provision, symptoms of dementia, and the model of the scheme.

There is no one-size-fits all.

What are the challenges of living with dementia in Extra Care Housing?

1. Understanding what ECH is

It can be difficult for people/families and even professionals to understand what level of support is available and how ECH differs from a care home.

2. Availability and accessibility of resources

Staff cannot always be available on demand. Funding the flexibility in ECH provision is a challenge and commissioners across the country use different approaches, whilst providers also offer different levels of service, meaning a lack of consistency across ECH.

A highly structured model of planned care calls, echoing domiciliary care, cannot provide the flexibility needed to maximise the potential of ECH. Across the country commissioners fund flexible provision in different ways.

3. Becoming familiar with a new home

It can be difficult for a residents living with dementia to familiarise themselves with a new place, with new people and new routines. Evidence suggests this can be more difficult as dementia symptoms progress, therefore the earlier a person moves in, the more likely they are to be able to live well in ECH.

4. The stigma of dementia

Other residents, families or staff can stigmatise a person living with dementia. This can make the person feel frustrated, excluded or angry.

5. Being able to maintain the boundaries of your own home

It can be a hard to maintain the boundaries of a private flat/apartment if the resident does not (or cannot) lock their front door. Some people find this can result in an invasion of their privacy.

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

Ron, living with dementia



6. Balancing safety and risk

Having an open door policy can be difficult to manage if staff believe the resident is at risk should they leave the scheme without support.

7. Advancing symptoms of dementia

For some people, as their dementia advances, it can be difficult for staff to support, and other residents to live alongside. High levels of confusion, aggressive behaviour, or night-time walking can be signs that the support available in the scheme is no longer sufficient.

8. Privacy can also be lonely

Staying in a private flat can be lonely. Sufficient staff need to be available to support residents to take up social opportunities and activities available onsite. Some residents living with dementia will require support to be reminded, prompted, and supported with navigating their way to and from their home and the activity. Without this support, residents might lack stimulation and become increasingly lonely and/or distressed.



“Lonely.. That is the main thing”
Pat, living with dementia

Arthur, 83, living with mixed dementia

Arthur moved into a large integrated scheme following a fall at home. His family decided he was no longer safe to live alone. Arthur’s symptoms have made it difficult to get used to his new surroundings. Arthur has five care calls a day to support with personal care and mealtimes.

Arthur can often become distressed in his flat because he doesn’t recognise it as his home. This means he often tries to leave the scheme. His family believe the staff should be spending more time with Arthur and often call up the manager to say so. They also believe the staff should stop Arthur from leaving and do not understand that staff in ECH cannot prevent Arthur leaving. However, the family rarely visit themselves.

Case Study

What helps a person living with dementia to live well in ECH?

1. Family/friend support

Family and friends can provide valuable support in between care call times. This could be to trips outside of the scheme, support with finance, shopping, or transport to medical appointments. They can also provide valuable advocacy with respect to the resident's tenancy or care and support plan.

It is important that people can choose to live in a scheme close to family support regardless of which local authority is paying for their care.

2. Positive relationships with staff

People do not have to get their care from the onsite team. However, the evidence suggests that having care from the onsite team can be beneficial because staff get to know the resident and can quickly recognise any changes in care required before a crisis occurs.



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

Alistair, family carer

3. Specialist dementia support

As dementia progresses, it can be beneficial to have support from specialist dementia staff or a specialist dementia day support opportunity.

Some organisations have named staff members who support residents living with dementia. Evidence suggests that this can help people stay living in ECH for longer.

People have told us that the opportunity to go to a external day centre or specialist dementia group can be beneficial, particularly as symptoms advance.

4. Familiar surroundings

Getting used to the environment is important. Evidence suggests that people living with dementia settle better in ECH if they move in when they are still able to develop new routines and make new relationships with staff and residents.

5. Assistive technology

Making use of technology can help people to live well in ECH. Many schemes provide residents with a falls alarm that is connected to the care team onsite. Some residents have video calling devices to keep in touch with family and friends, door alarms to notify the care team if they leaves their flat overnight, and memory clocks.

Evidence shows that many residents living in ECH could benefit from other technology that is available too, for example, a kettle tipper or tap sensor.



“I’ve got a sensor on the door... if [my husband] opens the door, it goes off. Then it rings downstairs. By the time that’s gone off, I’ve caught him”

Margaret, wife of Brian, living with dementia

6. A balanced community

ECH works best when the scheme can maintain a mixed needs community that includes people with no, low, medium and high levels of care need.

If the community becomes unbalanced, the scheme can feel increasingly institutional and people with lower levels of need do not want to move in.

7. Effective professional relationships

ECH provision for a person living with dementia can involve many different professionals from different organisations. This can include professionals from housing associations, care agencies, social services, advocacy organisations, health providers and commissioners.

Schemes work best when there are clear lines of communication between organisations. Different models of commissioning across the country are a challenge for ECH providers.

Key lessons for practice



1. People can live well with dementia in ECH if there is **sufficient support** in place. This might include support from a care package, a partner, family, friends, volunteers, or other residents.
2. **Different models work for different people.** It is a combination of variables, including the individual's personality, level of family support, model of scheme, relationships with other residents, relationships with staff, the physical space and environment, and their symptoms of dementia that will influence how well the person can live in ECH.
3. People living with dementia benefit from **specialist staff support** in ECH. This can include specialist staff roles that support with wellbeing and social inclusion. As symptoms progress, specialist social activity provision (e.g. day centre, Meeting Centre) could be particularly valuable for stimulation throughout the day.

4. ECH can support a person to live well with dementia through encouraging an ethos of **supported independence**. Onsite staff provide a level of reassurance that promotes positive risk-taking, supports independent living, and sustains informal care input.

5. Commissioning ECH for people living with dementia is challenging but **sharing practice** across local authorities, and across housing and care providers should be encouraged.

"I enjoy the garden when it's a nice day. And at least I don't have the problem of digging and weeding!"

Shirley, living with dementia





“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.”

Malcolm, living with dementia

What is this information in this booklet based upon?

The information in this booklet is based on research carried out by the Association for Dementia Studies at the University of Worcester. 100 residents, family carers, staff and adult social care professionals were interviewed to understand how ECH can support people living with dementia to sustain their wellbeing.

Thank you to all those involved in the DemECH project.

For more information about the project, please contact:

dementia@worc.ac.uk



Case Study

May, 78, living with Alzheimer's disease

May has some short-term memory loss, but her physical health is good. She moved in to Poplar Court 6 months ago. May has become familiar with her flat and the wider scheme, staff, activities, and other residents. She uses taxis to go to her bowls club nearby. She has been a member there for over 20 years.

May has never been much of a cook, so finds being able to get a hot meal at lunch time very convenient. She chooses her lunch using the weekly menu. For other meals, staff support her to make breakfast and light meals. One of her daughters lives nearby and helps with shopping. Her other daughter lives far away but both hold Lasting Power of Attorney and support managing finances.

May knows she might need more support in the future, but is confident she can get this from the staff at Poplar Court.



"I love it - it is my best move!"

Janet, living with dementia

This study/project is funded by the National Institute for Health and Care Research (NIHR) School for Social Care Research 102645/ER/UWTA-P180. The views expressed are those of the author(s) and not necessarily those of the NIHR or the Department of Health and Social Care.

