

Key Insights

Extra Care Housing: A booklet for people and families affected by dementia





What is Extra Care Housing?

Extra Care Housing is a type of **specialist housing** designed to support independent living.

Each resident owns, rents, or leases their **own private flat or apartment**.

There is care and support available onsite if, and when, you need 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.

Extra Care Housing often has **shared spaces, facilities and activities**. These will vary between different schemes, with larger schemes often having more facilities (e.g. shop, laundry, restaurant)

Organisations sometimes use different terms to describe Extra Care Housing, such as housing with care, housing with care and support, supported living, or assisted living.

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

William, living with dementia



Models of Extra Care Housing for people living with dementia

There are different models of Extra Care Housing for people living with dementia.



Integrated



Specialist



Separated

The majority of Extra Care Housing 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.

Sometimes a large scheme will have a **separate** area where people living with dementia live. This area can be smaller, have more focussed staff support and be a less busy environment to get used to.

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 change over time.

There is no one-size-fits-all. Different people will prefer different models of Extra Care Housing. The experience will also depend on how individual schemes are designed, operated and staffed.

“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, living with dementia





“It gave me new life because of the different activity groups that I enjoy”

George, living with dementia

What are the benefits of living in Extra Care Housing?

1. Having your own home

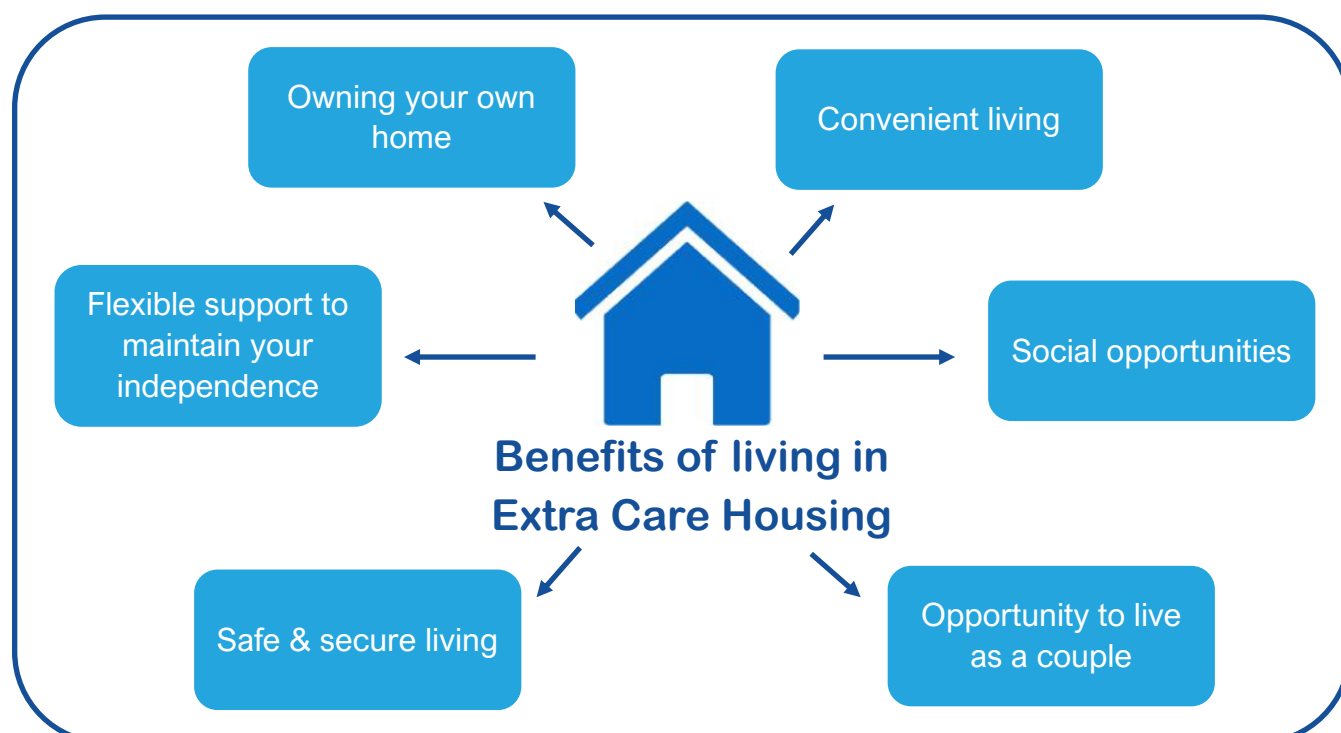
You have your own front door key. Your flat is your private space and can be filled with your own things. This can help you feel a sense of identity, control and ownership.

2. Flexible support to maintain independence

Staff can provide care and support if required. This support should work with you to help maintain your independence.

3. Safety and security

Knowing there are staff onsite can provide reassurance to you and your family that help is available if you need it. There are often multiple lockable doors between you and the outside, meaning it is hard for strangers to cold call at your front door.



4. Convenient living

Schemes are designed to be age-friendly (e.g. lifts, wide doorways for walking frames/wheelchairs). The property is managed, so you don't have to worry about gardening, DIY, cleaning (although some things might have to be paid for).

5. Social opportunities & activities

Activities, mealtimes, and shared facilities offer opportunities for social interaction without needing transport or needing to leave the scheme.

6. Opportunity to live as a couple

Couples can continue to live together. You can continue to care for each other, or access support from staff if you need it.



“I think people think “oh we don’t need it yet”, but my husband has mild cognitive impairment, that is going to develop... That’s the time to move... because then you get to know the community and everybody knows you for who you are”

Barbara, family carer

Mary, 78, living with Alzheimer’s disease

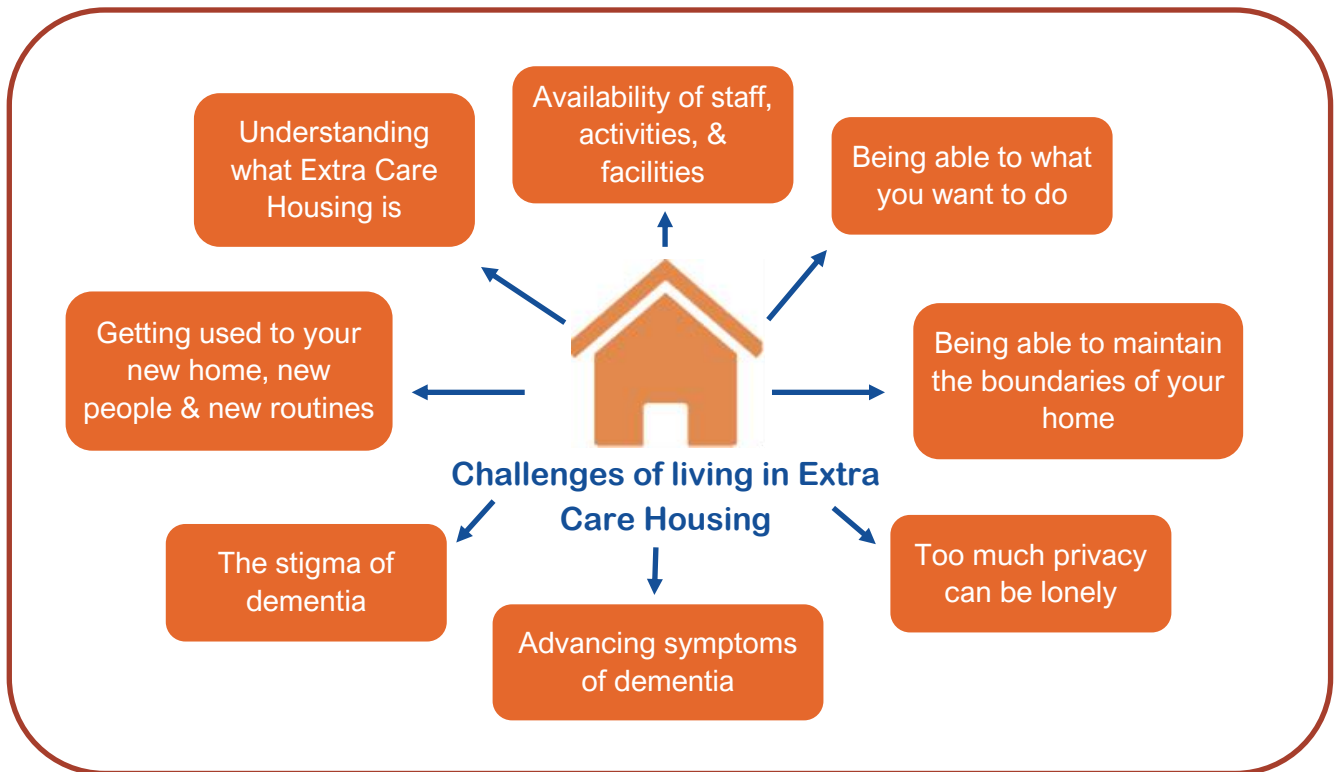
Mary has some short-term memory loss, but her physical health is good. She moved in to Poplar Court 6 months ago. Mary has become familiar with her flat and the wider scheme, staff, activities, and other residents. She uses taxis to go to her bowls club nearby. She has been a member there for over 20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

Mary 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.

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

Case Study

What are the challenges of living in Extra Care Housing?



1. Understanding what Extra Care Housing is

It can be difficult to understand what level of care and support is available and how Extra Care Housing differs from a care home. Extra Care Housing is not a care home. You have your own private flat with your own front door key.

2. Getting used to your new home

It can be difficult to get used to a new place, with new people and new routines. Evidence suggests this can be more difficult as dementia symptoms progress.

3. The stigma of dementia

Sometimes other residents, families or staff can stigmatise people living with dementia. This could make you feel frustrated, excluded or angry.

4. Availability and accessibility of resources

Staff are not always available. This can mean there are limits to how flexible care and support can be.

“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



5. Balancing safety and risk

It can be difficult to always do what you want to do if staff/others believe that it is something that is high risk. For example, you might want to go outside of the scheme, but staff are concerned about whether you will get lost outside and do not want you to leave.

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

It can be a hard to maintain the boundaries of your private flat/apartment if you do not (or are not able to) lock your front door. Some people find this to be an invasion of their privacy.



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

7. Advancing symptoms of dementia

Advancing dementia (e.g. confusion, aggressive behaviour or night-time walking) can be difficult for staff to support and other residents to live alongside.

8. Privacy can also be lonely

Staying in your private flat can be lonely. You might find that there are not enough staff available to support you to take up the social opportunities and activities available onsite.

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 often becomes 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 the staff cannot prevent Arthur leaving if he wants to. However, the family rarely visit themselves.

Case Study

What helps a person with dementia to live well in Extra Care Housing?

1. Family/friend support

Family and friends can provide valuable support in between care call times. This could be for trips out, help to manage your flat, shopping, transport to medical appointments, or advocating for you when discussing your tenancy or care plan.

Having your own private flat means that you have space to welcome family into your living room, and a kitchen to cook and share meals together.



2. Dementia-friendly design



Dementia-friendly design means that your flat and the wider scheme has been designed to support you to live well. This can mean clear signage around the building to help you find your way. It can mean that each floor in a building is painted a different colour so you can quickly recognise which floor you are on.

People have told us that being able to see their toilet from their living room is a helpful reminder of where the bathroom is. Some people have clear cupboard doors fitted so that they can easily find things in the kitchen if they find this difficult.

"I've always been on my own... So when I came here, I was a bit nervous... As soon as I got out and met people, I loved it"

Alice, living with dementia



3. Familiar surroundings

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

Some people find that having their own furniture can make their flat feel more familiar. Furniture can hold positive memories and be a reassuring sign that you are in your own home.



4. Positive relationships with staff

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



“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”

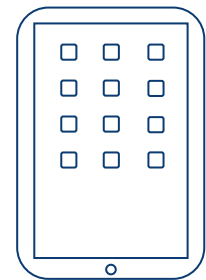
Margaret, family carer

5. Assistive technology

Making use of technology can help you to live well in Extra Care Housing. 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, or memory clocks to help tell the time and day.

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



6. 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 can support you as your symptoms change. Evidence suggests that this can help people to stay living in Extra Care Housing for longer.

People have told us that the opportunity to go to a external day centre, Meeting Centre, or specialist dementia group can be beneficial, particularly as symptoms advance. This can provide important social activity and stimulation outside of your flat.

Can Extra Care Housing be a ‘home for life’?

A ‘home for life’ means that you can stay living in that home for the rest of your life. It means that you do not have to move again once you have moved in.

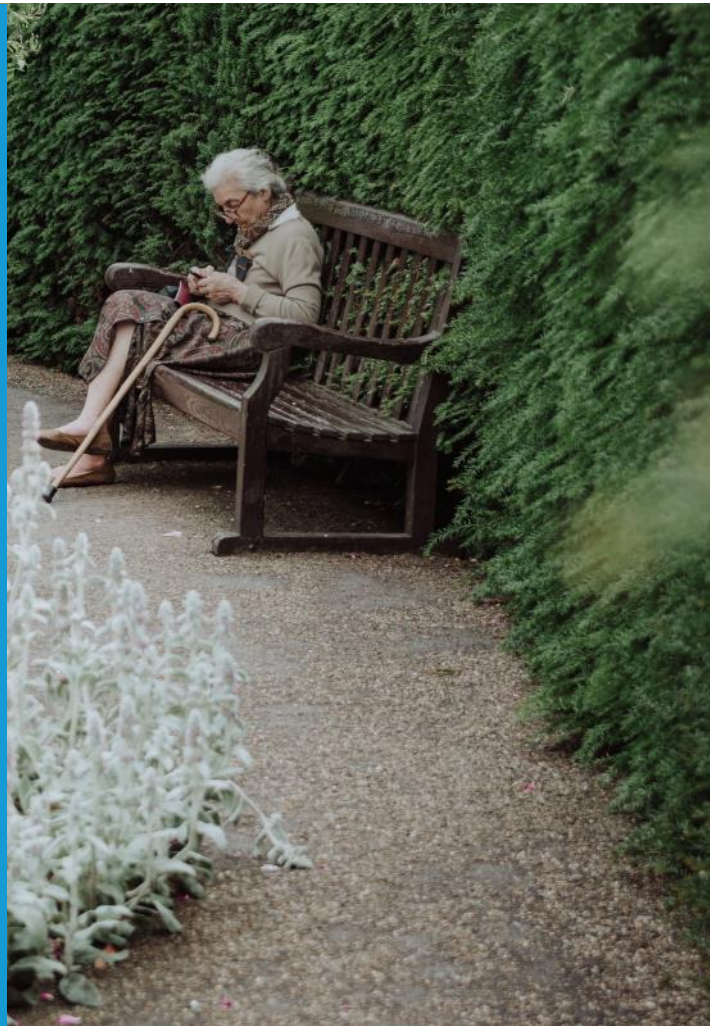
Some people living with dementia will be able to live in Extra Care Housing for the rest of their life. However, Extra Care Housing cannot guarantee to be a ‘home for life’ for everyone.

Some people might develop symptoms or other health conditions that would benefit from more care and support than is available from staff in Extra Care Housing. For these people, a move to a smaller environment with more intensive staff support might be in their best interests in the future.

Evidence shows that the earlier you move in to Extra Care Housing, the more likely you are to live well there for longer. Maintaining positive and supportive relationships with family and friends can also help you to live as well as possible in Extra Care Housing.

“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



David, 85 and Sally, 83, both living with dementia

David and Sally have been married for over 50 years. They live in a dementia specialist Extra Care Housing scheme. Family support with finances, weekly shopping, medical appointments, and social visits. Staff support with regular welfare visits.

Sally does the cooking and cleaning. This is important to her – she says she would feel “useless” if she didn’t as this is something she has “done all her life”.

They regularly walk around the floor that they live on. Sally will often join in the activity in the shared lounge after being reminded by staff that it is on.

David prefers to stay in their flat and read the paper or watch the

television. David has a photo of himself as a young man in the army, staff often use this photo to make conversation with David. David enjoys this opportunity to reminisce as his time in the army was an important part of his life and is still strong in his memory.



Notes

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 adults social care professionals were interviewed to understand how Extra Care Housing can support people living with dementia to sustain their wellbeing.



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.