

# Housing Learning & Improvement Network

Care Services Improvement Partnership 

Health and Social Care  
Change Agent Team

## Extra Care Housing is not the Answer for Everyone with Dementia

Is Extra Care Housing a complete solution to the care and accommodation needs of older people with dementia?

**Sue Garwood** argues that choice and a range of services are needed

It is really encouraging to see the Department of Health backing the development of Extra Care Housing for older people, both through the issuing of grants, and through its investment in the Housing LIN (Learning Information Network), but I am concerned that there seems to be a bandwagon rolling apace. The message about Extra Care for people with dementia appears to be “go out and do it”, without simultaneously raising awareness of complexities, caveats, and areas for debate. I believe that Extra Care housing may not be best for everyone.

Despite the social policy rhetoric about person-centred and individualised service delivery, sweeping generalisations about what people want and need are still being made. And when promoting service solutions, insufficient attention is still being paid to the fact that all people are different and one person may need or prefer a different option from that which suits another.

In the first part of this article, I focus on the principles and assumptions which underlie many people’s approach to policy and service development for older people.

Having considered the philosophical context which many use as justification for the policies and services they promote, the second part of the article focuses on the opportunities and limitations of Extra Care housing for meeting the needs of people with dementia.

### COMMON ASSUMPTIONS

Certain assumptions or beliefs (explicit or implicit) are current in relation to older people’s aspirations and needs. These require scrutiny in the context of service provision for older people with dementia. They include:

***Everybody wants to remain in their own homes for as long as possible.***

While this may be true of many people, and indeed is supported by research, it is by no means the case for everybody. Yet many Social Services assume this aspiration exists, and do not give

people the option to move if they can continue to be supported at home.

The person with dementia living in no: 7 The High Street, who is supported by an intensive domiciliary care package may well feel isolated and abandoned. While their care may be “managed” by Social Services, the resident may feel unfulfilled, bored and frightened. In such circumstances this person may prefer to move somewhere which offers increased safety and security, greater opportunities for flexible support and care, and stimulating activities and social contact, rather than have additional support where they are. In this case, an Extra Care scheme may be the ideal solution.

***Everybody wants to remain independent for as long as possible and it is in the individual’s best interests to do so.***

One of the key tenets of current government social care policy is to “promote independence”. What do we mean by “independence”?

Many people interpret independence as self-reliance and autonomy - as “doing things for yourself”. For example, making a cup of tea, with help if necessary, rather than having someone do it for you; managing your own affairs; doing your own shopping, cooking, and cleaning. While many older people may want this, there are some who would prefer not to have to continue the unequal struggle and may wish for someone else to take responsibility and do things for them.

If, on the other hand, by independence we mean self-determination and choice – an interpretation that I personally prefer – we need to accept that while many people will choose to do as much for themselves as they possibly can, and will derive considerable fulfilment and self-respect through doing so, others may not. Some individuals may happily trade what is traditionally seen as independent living for mutual interdependence or even dependence.

But even if we accept the second interpretation of independence, some people with dementia are genuinely limited in their capacity to exercise it. Should “promoting independence” be seen as the most important principle governing our approach to service development for everybody? Should not something subtly different be paramount - fulfilment, a sense of well-being and personhood, maximum quality of life – however these are realised for a particular individual? Or at least have equal status with self-determination and choice?

Maximising opportunities for the individual to exercise self-determination and choice, alongside carers seeking the best option(s) for promoting well-being, seem better guiding principles for people with dementia than the superficial application of the promoting-independence principle. Where people have the capacity to self-determine or choose, they should have the right to determine the hierarchy of principles which matter to them, and what that means in terms of the practical choices they make – including the right to a more dependent regime if they so choose.

***To provide anything less than a fully self-contained unit is discriminatory.***

The physical expression of the “doing-things-for-yourself” interpretation of independence is having self-contained living accommodation with fully equipped kitchen. Whilst for many people this feature of familiarity is welcome and useable, albeit with help and support, others may actually prefer the companionship and stimulation of preparing a meal together with a small number of other people in a shared kitchen.

Those in the more advanced stages of dementia – given that high quality provision is expensive – may achieve greater fulfilment having a shared kitchen, increased one-to-one contact with care staff, and more social stimulation, than having a splendid fully self-contained flat within

which to feel isolated. Whilst these two are of course not mutually exclusive, in a situation where funding is limited and design militates against, or promotes, a sense of inclusion, to interpret people's rights too narrowly as a self-contained flat is to disadvantage those with other needs and preferences.

***To exclude someone with dementia from Extra Care housing is discriminatory.***

This may be the case if the reason for turning down an application is based purely on a diagnosis of dementia. If, on the other hand, it is genuinely believed that the facilities and services are not suitable to meet that individual's needs, staff would not be acting in the individual's best interests to accept the application.

There is a strong body of opinion which sees having one's own home in the form of a tenancy, lease or freehold as a fundamental and empowering human right. I agree. But in some circumstances, other rights and needs are more important, and it is not always feasible to preserve them all.

**BENEFITS AND LIMITATIONS OF EXTRA CARE**

I believe Extra Care Housing is an excellent model for providing accommodation and care to many older people, but, as I've already made clear, not necessarily for everybody. My reasons for taking this position in relation to some people with dementia are explained below. I do not intend to explore the suitability of Extra Care housing for people who develop dementia whilst living there. There is little doubt that an Extra Care housing setting can prolong a person's ability to live in their own home. Where an individual has a sense of belonging and is accepted by others as part of the community, where someone feels at "home" and is familiar with the surroundings, Extra Care's unique combination of services, facilities and opportunities can enable a person with dementia to live a fulfilled and meaningful life to a significant degree.

The question I am primarily considering is the point at which people with dementia move from their current abode into Extra Care, and whether there comes a time when the features and benefits of Extra Care are no longer relevant, important, or of benefit to the person with dementia who is no longer coping in 7 The High Street.

**The Features of Extra Care Housing**

So, what, for the purposes of this article, are the fundamental characteristics of Extra Care housing?

- It is housing, not residential care.
  - People have tenancies or leases which provide security of tenure
  - There is usually has a "quiet enjoyment" clause
  - Residents have control over who crosses their threshold and have the right to refuse care
- Its ethos is to promote independent functioning
- There is 24 hour domiciliary care and support available on site
- Usually, but not inevitably, it comprises a cluster of fully self-contained units
- There is usually a range of communal facilities with social or communal activities facilitated by members of staff
- It is often purpose designed and built
- Commonly, there is controlled access to the building(s) with technological door-entry systems

- There is usually a back-up alarm system
- Increasingly there is a range assistive technology and telecare
- There is a housing management service

Despite common themes, no two Extra Care schemes are the same, and some are better than others in terms of design and/or service provision. That said the unique configuration of services and facilities does offer many benefits to most people.

### **The Benefits of Extra Care Housing**

Security of tenure enables a sense of self-determination and choice. Further, people who live in this type of arrangement and who receive state benefits have a greater disposable income than their counterparts in residential care.

A purpose-designed self-contained flat can promote maximum independent functioning and permit the opportunity to remain private, while having access to communal facilities offers the individual the choice to participate in activities with other residents. Building security, back-up alarm and round-the-clock care and support can provide a sense of safety and security and still permit residents to come and go as they please while the existence of telecare can facilitate non-intrusive monitoring.

A further characteristic of Extra Care housing – the presence of care and support staff round the clock – enables a more flexible and responsive service than is possible in someone's home in the dispersed community. Further, much of the worry of maintaining a home is removed because staff and systems are in place to deal with tricky responsibilities such as repairs and maintenance.

*If Extra Care offers all these advantages, surely anyone would be better off in such a setting?*

I have visited Extra Care schemes which aim to meet the needs of people with dementia and spoken to a range of people involved in the development and operation of such services. Most of these individuals concur that Extra Care is not suitable for everyone with dementia. The consensus seems to be that there is a window of opportunity when the move should take place. The individual needs to have some understanding of what is being proposed, agree to it and have sufficient memory intact to develop a sense of the new surroundings as home. The person also needs to have the capacity to build relationships with other residents.

Where people who were beyond this point have moved in to schemes, the situation has broken down and they have had to move to a care home. Another determining consideration is the way in which an individual's dementia presents. Some of the more extreme, challenging behaviours can be a contra-indication for a housing model, unless there is good reason to believe that the service configuration would mitigate these behaviours.

There is no simple clear-cut criterion for determining who Extra Care is suitable for, and who would be better off in a different setting. It is an area which deserves detailed research. People in the moderate to advanced stages of dementia may be better off and more fulfilled in a specialist residential or nursing care setting, but it does not seem to be quite as straightforward as that. It is very much a matter of assessing each individual case on its merits.

The assessment should be undertaken by a dementia specialist. Ideally the same member of staff should undertake all assessments so that s/he builds up expertise based on an in-depth understanding of dementia, the characteristics, strengths and limitations of the Extra Care scheme, and of the other services on offer.

It is essential to involve the individual in the process as far as possible and gather a picture of personality and history. It is important that the person wishes to retain as much independence as possible is important, and it is also key that there are opportunities for mutual assessment between the scheme and the applicant. It is also vital that any move is preceded by careful preparation.

## **WHEN EXTRA CARE IS NOT SUITABLE**

What is it about the housing model which makes it less than ideal for those with extreme behaviours or severe cognitive impairment? Let us look at the features of Extra Care outlined above in considering this question.

### **Tenancies or leases.**

These are legally binding contracts. An individual who lacks the capacity to understand, at least to a basic extent, what he or she is signing up to, should not be asked to sign the contract. If there is not a large number of tenants holding valid tenancy agreements which define that they are living in their own homes, the scheme may be deemed to be providing accommodation and care together within the meaning of the Care Standards Act and be registrable as a care home.

Even though the signature of an attorney with authority under Lasting Power of Attorney would legitimise the tenancy, the attorney cannot ensure that the tenant understands and complies with terms of the tenancy such as “quiet enjoyment”. If an assessment identifies that someone is unlikely to be able to comply, it is arguably not fair on that person or the other tenants to offer this individual a vacancy.

A benefit of holding a lease or tenancy is that it allows residents to have control over who crosses their threshold and gives them the right to refuse care. It could be argued, however, that in the case of someone with severe cognitive impairment, such rights may be meaningless.

### **Care**

24-hour domiciliary care and support is available in most Extra Care schemes. This enables considerable scope for flexible and responsive service delivery which is why Extra Care housing is a very good resource for many people with dementia.

This arrangement is, however, is also one of the key limitations of Extra Care for those needing particularly intensive input, responsive care and close supervision. If someone needs continual contact with a staff member, if the care has to be very variable from hour to hour and day to day, if the individual needs most things done for him or her, or requires continual prompting and guidance, it is difficult to provide that type and level of care in a housing setting.

Domiciliary care tends to be purchased by the hour and charged for on the basis of the local non-residential charging policy. Such a high staffing ratio, and staff who have the necessary skills, are likely to prove expensive and very often care commissioners are not willing to increase the care specification sufficiently to provide the level of service needed.

Additionally, care and service provision of this intensity often results in an institutional feel which resembles residential care much more than it does housing.

### **Design and Technology**

There is little doubt about the advantages of designing buildings for people with dementia

specifically in mind. This applies both to housing and residential care and many of the same principles apply to both. Assistive technology, too, is undoubtedly a huge asset if sensibly and ethically applied – for example, door opening and movement sensors; flood, gas and smoke detectors. Although not unique to housing, telecare complements a housing model well and can help to overcome some of the downsides of a housing model for people with dementia. However, it cannot compensate for them all.

The ideal design and technology for people moving in with dementia in the advanced stages may not always be compatible with that commonly deployed in new Extra Care schemes in order to promote autonomy, freedom of movement, independent living and choice.

With regard to design, for example, smaller scale, more open plan facilities, and possibly shared kitchen, are likely to be more conducive to delivering person-centred care cost-effectively to people in the more advanced stages of dementia.

Technologies which rely on the individual to activate them may well be counter-productive. Most Extra Care schemes have a door entry system based on codes or fobs which enable residents to come and go as they please but restrict access to strangers. These can be quite complicated for residents to use, with the result that rather than being an advantage to someone either unable to use the system, or deemed too much at risk, they may result in a sense of frustration.

The back up alarm is a useful feature of Extra Care. However, unless the individual has learnt to use the pull cord and alarm pendant whilst still capable, or moves in while he or she has the capacity to recognise and use these, there is a risk of misidentification and the likelihood of being unable to use the alarm in an emergency.

## **RESIDENTIAL CARE BY ANOTHER NAME?**

In combination, these features of Extra Care housing are arguably not ideally suited to those with extreme cognitive impairment or behaviours. It is true that, apart from the contractual basis, all the distinctive housing features described could be modified to be more suitable to the needs of the person in the advanced stages of dementia. But if a scheme is stripped of those aspects which make it housing, and instead resembles residential care in almost every respect, does it still offer advantages which make it a superior model for those with advanced dementia? And is it still housing in anything other than name? On the other hand, if the provision has not been tailored to cater for the higher level of needs, at least from the care perspective, isn't the individual with dementia then at a distinct disadvantage?

If the individual is unable to gain fulfilment from the advantages afforded by a housing model – independence, self-determination and choice, if the tenancy is for all practical purposes meaningless, and the person needs a degree of intensive help and supervision which makes a fully self-contained flat at best a waste of money, and at worst an isolating hindrance, why move in to an Extra Care scheme? Would not a specialist care home designed specifically for this group, both physically and in terms of service provision, offer not only a more honest solution, but also on balance a more fulfilling and meaningful one for such individuals?

These questions need open and honest debate and research, not superficial soundbites.

## **THE CASE FOR CHOICE OF PROVISION**

Irrespective of the conclusions reached on these questions, because no two people are the same, we should not be putting all our development eggs in one basket.

We should consider the range of needs of people with dementia and make our development decisions in an informed, thoughtful way, pushing out the boundaries but working within existing legal and financial frameworks.

Some specialist providers are developing a combination of Extra Care housing, a resource centre, and specialist residential-cum-nursing home care for people with dementia. It would be sad if the “Extra Care as the universal panacea” lobby resulted in a reduction of such mixed developments.

We should be aiming to develop a variety of innovative, quality provision so that people with dementia and their families have a real choice.

## Other Housing LIN publications available in this format:

<u>Factsheet no.1:</u>	<b>Extra Care Housing - What is it?</b>
<u>Factsheet no.2:</u>	<b>Commissioning and Funding Extra Care Housing</b>
<u>Factsheet no.3:</u>	<b>New Provisions for Older People with Learning Disabilities</b>
<u>Factsheet no.4:</u>	<b>Models of Extra Care Housing and Retirement Communities</b>
<u>Factsheet no.5:</u>	<b>Assistive Technology in Extra Care Housing</b>
<u>Factsheet no.6:</u>	<b>Design Principles for Extra Care</b>
<u>Factsheet no.7:</u>	<b>Private Sector Provision of Extra Care Housing</b>
<u>Factsheet no.8:</u>	<b>User Involvement in Extra Care Housing</b>
<u>Factsheet no.9:</u>	<b>Workforce Issues in Extra Care Housing</b>
<u>Factsheet no.10:</u>	<b>Refurbishing or remodelling sheltered housing: a checklist for developing Extra Care</b>
<u>Factsheet no.11:</u>	<b>An Introduction to Extra Care Housing and Intermediate Care</b>
<u>Factsheet no.12:</u>	<b>An Introduction to Extra Care Housing in Rural Areas</b>
<u>Factsheet no.13:</u>	<b>Eco Housing: Taking Extra Care with environmentally friendly design</b>
<u>Factsheet no.14:</u>	<b>Supporting People with Dementia in Extra Care Housing: an introduction to the the issues</b>
<u>Factsheet no.15:</u>	<b>Extra Care Housing Options for Older People with Functional Mental Health Problems</b>
<u>Factsheet no.16:</u>	<b>Extra Care Housing Models and Older Homeless people</b>
<u>Case Study Report:</u>	<b>Achieving Success in the Development of Extra Care Schemes for Older People</b>
<u>Technical Brief no.1</u>	<b>Care in Extra Care Housing</b>
<u>Technical Brief no.2</u>	<b>Funding Extra Care Housing</b>
<u>Technical Brief no.3</u>	<b>Mixed Tenure in Extra Care Housing</b>
<u>Viewpoint no.1</u>	<b>The Challenge of Providing Extra Care Housing for People with Dementia</b>
<u>Viewpoint no.2</u>	<b>Tenancy Issues: Surviving Partners in Extra Care Housing</b>
<u>viewpoint no.3</u>	<b>Moving towards a Home-owning Democracy</b>

Published by:  
Housing Learning & Improvement Network  
Health and Social Care Change Agent Team  
Department of Health  
Wellington House, 2nd Floor  
135-155 Waterloo Road  
London S1E 8UG

Administration:  
Housing LIN, c/o EAC  
3rd Floor  
London SE1 7TP  
020 7820 1682  
housinglin@cat.csip.org.uk  
www.changeagentteam.org.uk/housing