

# Opening doors to independence – summary

A longitudinal study exploring the contribution of extra care housing to the care and support of older people with dementia

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The images used do not represent the people used in this research.

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# Summary

Over 750,000 people in the UK have dementia; by 2050 this will rise to 1.8 million. The likelihood of developing dementia increases with age, so as the population ages so does the incidence of dementia. Extra care housing is becoming established as a significant model of housing with care provision for older people.

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## 1.1 Background

Housing 21, with the support of an Innovation and Good Practice grant (IGP) from the Housing Corporation, and in partnership with Dementia Voice and the University of the West of England, Bristol embarked on a three year tracking study to explore what happens to people with dementia in extra care housing.

## 1.2 Research aims

- To evaluate the contribution that extra care housing can make to the long term care and support of people with dementia.
- To make recommendations for good practice and assess the limitations of extra care housing.
- To capture the views of older people with dementia.

The findings presented here are from a study tracking people with dementia in Housing 21's extra care housing courts. Data was collected on 103 people and 36 people with dementia were interviewed up to five times from July 2003 to October 2005.

## 1.3 Key findings

Extra care housing is providing a good quality of life to the majority of residents who have dementia, many of whom are very old and additionally have complex health needs.

Many older people with dementia recognise that, of the housing options available to them, extra care is more suitable to helping them maintain their independence:

**“It's got everything really...it can never equal living in a family but it is the next best thing.”**

People with dementia are demonstrably able to live independently for 2.13 years on average - nearly as long as residents without significant cognitive impairment. This suggests dementia alone does not have a negative impact on a person's potential to live independently in extra care housing.

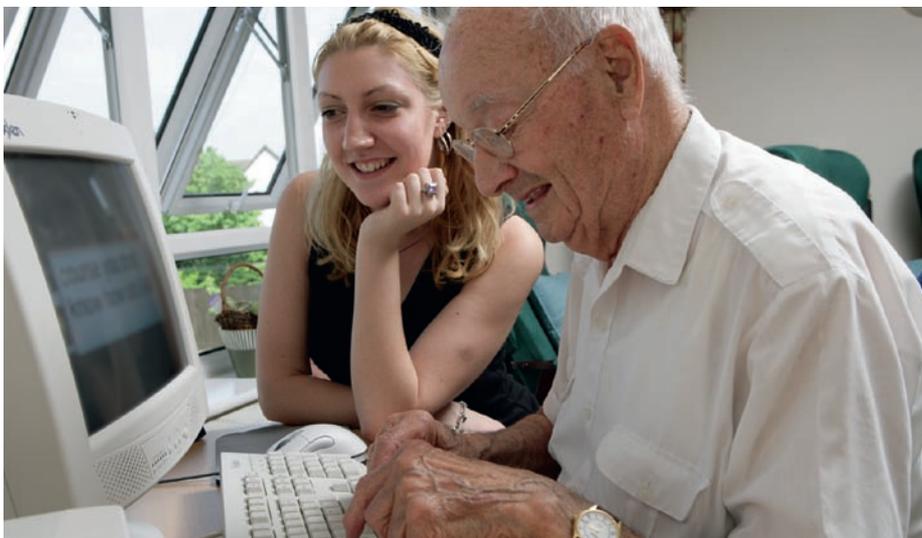
The immediate policy context outlined in the recent Department of Health White Paper presents a number of opportunities for the preventative role of extra care and for increasing use of extra care housing as a site for the delivery of community health services to people with complex needs, both to residents within extra care and the wider community.

The benefits of extra care housing are recognised by relatives of people with dementia. In some cases, family relationships were said to improve when people with dementia moved to extra care housing. Residents and relatives were reassured that there was someone on-site to 'keep an eye' on things. Nearly all of the residents with dementia were frequently visited by family members who provided much informal support.

Extra care housing is providing a good quality of life to the majority of residents who have dementia, many of whom are very old and additionally have complex health needs.

#### 1.4 A home for life?

- Extra care is providing a 'home for life' for half of its residents with dementia, though some people do move on.
- Most people were over 84 years old when they first moved into extra care.
- Most residents with dementia were also of 'high dependency', in that they had care packages of around ten hours of personal care per week, and many were reported to have other health problems apart from dementia.
- 16 people have been resident for the entire duration of the study and they have now lived in extra care housing for an average of 3.6 years.
- Half of tenancies that ended over the course of the study resulted in moves to other care settings – mostly to nursing care.
- Risk, challenging behaviours, conflict with staff and other residents and appearance of distress were often reported as trigger factors resulting in moving on. Several people died very soon after the move which perhaps calls into question whether a move was appropriate.
- Worsening dementia was a factor in nine of the cases of moves to nursing care (41%).
- Of the residents who died over the course of the study, 66% were in hospital at time of death. Most had been admitted a few days before they died because of a sudden illness.



## Where extra care is positioned as part of an overall strategy for older people... it is more likely to be the case that community health services use extra care housing as a site for service delivery.

Complexities in how long term care is funded can impede the ability of extra care to provide a 'home for life'. The following example illustrates:

### Example

#### *Continuing care – increasing funding pressures – efficiency drivers*

An 87 year old woman moved into a part sheltered and part extra care court (Housing 21's term for scheme) in February 2005. She was diagnosed with dementia prior to the move. She had been referred to the court by social services and moved in due to health reasons and so she could be closer to her family. Previously she had lived some distance away so her family were unable to offer any support.

She was recently diagnosed as terminally ill from cancer. At the time of reporting she was thought to have only a few weeks to live. The local authority which funded her care was keen from this point to refer her to a hospice so that she would no longer be funded from social care budgets but should transfer to '*continuing care*'. Continuing care funding should be available in any living environment and is not limited to care homes or hospices so there has been some confusion about the application of this policy.

The resident's GP, the court manager and her family all felt that an enforced move was against her best interests and were fighting to maintain her in the court until her death. Though her physical health had declined rapidly, (her care plan had recently been reviewed and increased from 11 to 14 hours per week) her mental state and quality of life had improved since she moved in. She did not display awareness of the nature of her illness and became agitated and distressed if she had to go off-site as she preferred to be at home as much as possible.

Palliative care was on standby from Macmillan nurses at the time of writing. It is clearly in no-one's interests that she should be moved as this would cause unnecessary upheaval at an already distressing time. The resident's GP, family and court staff were all hopeful that she would be able to live out the rest of her life in the extra care court she considered home.

### 1.5 Access to health care

This study shows that many residents with dementia in extra care housing have complex health needs and most of those health needs are being met within the extra care housing setting.

Where extra care is positioned as part of an overall strategy for older people, including health, housing and social care, it is more likely to be the case that community health services use extra care housing as a site for service delivery. However, it is striking that access to health services in many other areas was more ad-hoc.

Though some extra care residents are frequently admitted to hospital, their in-patient stays are shorter than for the general population of older people. This opens the door to maximising the use of extra care as a preventative resource.



Extra care does not put an additional strain on health service resources as people have health care needs wherever they are living. In theory, extra care has potential to reduce costs and thus prevent more costly intensive services. In many ways, if health care service providers maximise the use of extra care as a site from which to deliver community health care, then delivery of health services should become more efficient.

### **1.6 Good design is not enough**

Good design has a key role to play in terms of improving the quality of life for everyone who lives and works in extra care housing. It is particularly important that people with dementia have a stimulating environment and good opportunities for social interaction. Therefore, the ability to move around the building independently is particularly important to people with dementia.

Where possible, ‘escorting hours’ should be built into the support element of block care contracts so that people with dementia and mobility problems can be enabled to use and make the most of the wider facilities in the court.

The evidence base for the most effective design features to improve orientation for people with dementia is limited. While certain design features are often deployed to aid orientation, such as maximising natural light, adding landmarks and colour-coding circulation routes, the evidence base for the effectiveness of these features is limited. There is a need for more rigorous investigation of the most effective design features for people with dementia. Any evaluation of design should involve older people including those with dementia as well as other residents and staff in extra care housing.

### **1.7 Integration or specialisation?**

One court in this study has a specialist cluster of eight flats designed to house people with dementia. The specialist unit is accessed through security doors – residents in the rest of the court do not have access. The specialist cluster comprises eight flats, (two of which are two-bedroom and designed to house couples) a corridor with seating areas, a dining facility and a residents’ lounge.

#### **The benefits of a specialist design**

- Specialist care and support can be targeted to people who need it most.
- Less people have moved on to other care settings from the specialist court, but this is partly due to the fact that it is in a rural location so options are limited.
- Nearly all residents in the specialist cluster had frequent orientation problems and were reported to wander, but this was less problematic to the management of the court than for integrated designs.



However, its effectiveness as a dementia specific environment was limited for several reasons:

### **Limitations of a specialist design**

Housing couples in the specialist cluster was problematic when only one partner had dementia. In one case, a couple moved out of the cluster as the partner without dementia felt it was a constraining environment. They are now living together in one of the 'ordinary' flats.

The prevalence of memory problems amongst the wider resident population made it difficult to target intensive care and support to residents in the specialist cluster.

Lack of detailed information from health and social care services about potential residents at the time of referral meant it was sometimes difficult to assess their suitability for housing in extra care.

The remaining courts were of integrated design, meaning that people with dementia were housed alongside people without cognitive impairment and shared facilities on the court were available to all residents.

The extent to which people with dementia can and should live in close proximity to people with no cognitive impairment is an under-researched area and often discussed. People without dementia (in the non-specialist courts) were interviewed as part of this study. Some people had developed close friendships with neighbours with dementia, and others felt they were aware of problems associated with memory loss and went out of their way to be kind and supportive.

Awareness of dementia and its impact, particularly on behaviour, can do much to allay fears and reduce stigma, so housing providers should provide good information about the condition to all residents.

There were a few reports of people with dementia being discriminated against by other residents, particularly where there were attempts to exclude them from social activities.

## **1.8 Flexible care and support**

The flexibility of care and support provision is one of the key strengths of extra care housing. This benefits all residents, though people with dementia particularly benefit from having carers who are familiar with them. However, increasing resource pressures are threatening the ability of extra care housing to support people as their needs fluctuate and change.

Continuity of care is very important to people with dementia. Building a rapport with carers has a positive impact on their quality of life. However, staffing shortages resulting in increased use of temporary staff is undermining the ability to provide continuity of care in an increasing number of courts.

Providing a stimulating environment is key. Therefore it is important that day centres, restaurants and social activities (if provided) are set up and operational as soon as new courts open.

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### 1.9 Staff training and awareness

There is a need for more specialist training about dementia and appropriate qualifications for care staff.

Most care staff interviewed as part of this study had some awareness of the nature of dementia and its implications for the support and care needs of the residents they worked with. However, few staff had received dementia specific training relevant to their current roles and this clearly had a negative impact on how effective some care staff were when working with people with dementia.

There are no training and qualification guidelines that are specific to extra care housing. The Department of Health has been working with the Housing Corporation to develop a range of extra care 'competencies' in recognition of this.

Several organisations, including Dementia Voice, have developed dementia specific training packages and a training programme on dementia is currently being rolled out in Housing 21's extra care housing courts. However, the training packages were felt by some care staff to be rather basic, too short and too broad.

## People with dementia and their relatives value the security offered by extra care housing.



### 1.10 Balancing security and risk

People with dementia and their relatives value the security offered by extra care housing. The social alarm system was a major factor giving peace of mind and reassurance. However, nuisance behaviours were associated with use of the alarm system – frequent calls without apparent reason were often a trigger for a person with dementia to move to another care setting.

Appropriate training should be provided to alarm centre staff (and extra care staff who deal with call responses) in terms of communicating with people with dementia.

Further research is needed to evaluate whether alarm systems other than the traditional ‘pull cord’ alert should be incorporated into housing environments that increasingly house people with dementia.

Other assistive technology was an under-used resource in extra care housing – this despite its potential to overcome physical and cognitive impairments, counteract isolation, monitor risk and promote safety for people with dementia.

Staff, relatives of people with dementia and senior local health and social care managers all recognised the benefits of appropriately used assistive electronic technology. However, the study found only three examples where this was being used, in spite of Housing 21’s investment in hardwiring when courts were first built.



Technology should be used sensitively to ensure that security is maximised without a negative impact on autonomy. ‘Wandering’ is often considered to be a risky behaviour that challenges the ability of extra care housing to support people with dementia, but this study found very few examples where this type of behaviour was problematic.

Greater use should be made of electronic assistive technology to support residents with dementia. This should be undertaken in the context of well developed, person centred risk assessment and management processes.

### **1.11 Challenging behaviours or challenging staff perceptions?**

The study recorded incidence of various behaviours associated with dementia. It raises the question of whether ‘challenging behaviours’ are really problematic for the individual and the management of the court or rather are barriers to providing appropriate support. For example, frequently pulling the emergency alarm cord for no apparent reason was often cited as a trigger for moves to other care settings. However, the emergency alarm is a key factor in giving residents and their families peace of mind and residents are encouraged to use the alarm when they need to. Just because a reason is not apparent to staff does not mean that there isn’t one. Staff dealing with the alarm system should receive specialist training in communicating with people with dementia.

Wandering should not be considered as a ‘challenging behaviour’. Though people with dementia were widely reported as having orientation problems, and many wandered frequently, examples of this being problematic were rare.

Staff felt that aggressive behaviour may lead to moves to other care settings, but even then, appropriate training could enable staff to identify triggers for aggression and hopefully avoid its recurrence.

### **1.12 Policies and strategies**

Extra care housing is most effective when it is delivered as part of an integrated older people’s strategy which involves health, housing and social care services.

Joint working is vital to the success of extra care housing for people with dementia and all residents. Interdisciplinary working is essential to effective assessment, referral, regular service reviews and ongoing service provision.

### **1.13 Achieving a good quality of life**

Independence is important to all older people including those with dementia. Like other older people, people with dementia are citizens and consumers, these rights do not dissipate when they have dementia, though some public policy statements still treat people with dementia as passive recipients of services.



The balance between independence and isolation is one of the key challenges in maintaining a decent quality of life for people with dementia. Promoting independence is a core element of the extra care philosophy and culture, but this approach does raise questions in terms of how easy it is to determine the desire of a potential resident to be independent – particularly when one takes frailty levels and health needs into account. A potential resident’s previous accommodation often impacts upon their ability to live independently in extra care housing. For example, several people in the study were previously in residential care. Some of them found it difficult to live independently and adjust to the more enabling culture of extra care. Having their own flats made some people feel much more isolated. However, provision of appropriate support from staff can help people to regain independence.

The previous point raises a key question – given that frailty levels in extra care had increased over the study period, and most residents fulfil the criteria for ‘high dependency’, is it appropriate to speak of extra care as a ‘balanced community’? The courts participating in this research were all primarily operating as a replacement for residential care. In this case, is it appropriate to expect all residents to be able to live independently?

Social activities play a major role in well-being for people with dementia. Activities that provide mental stimulation and involve other people from the wider community were found to be particularly beneficial. However, resource constraints and pressures on staff time meant that opportunities for staff to maximise provision of social activities were compromised.

The potential for relatives and friends to be involved in the care and support of residents is one of the major benefits of extra care housing. People with dementia and their families were particularly happy with this aspect and felt it made extra care housing a more ‘homely’ environment than other housing options that may have been available to them.

Links to the wider community are important to people with dementia. Provision of on-site facilities like shops, hair salons and restaurants can facilitate better opportunities for community engagement and social interaction.

Though social interaction is important to people with dementia, the opportunity to enjoy time alone in a private and safe environment was a crucial element of quality of life for many residents in this study.

People with dementia value the feeling of being cared for, and the peace of mind they get from living in extra care housing.

Good diet and eating regularly is important to everyone, particularly people with dementia. Some people with dementia were reported as having improved well-being (and less challenging behaviour) as a result of using on-site restaurants.

This study recommends that facilities for communal dining should be provided in extra care.

People with dementia should, where possible, be involved in the planning, purchasing and preparation of meals as this can promote rehabilitation and independence, particularly if meal preparation is included formally in care plans.

The door is open for all stakeholders involved in the delivery of extra care to maximise the preventative role of extra care housing.

Whilst making meaningful new friendships is difficult in later life, and particularly so in an environment where people only live for a relatively short period of time, the potential for friendships and mutual support is an aspect of living in extra care housing that is especially valuable to people with dementia. The following quote from a person with dementia and a friend with mobility problems illustrates:

Resident 1: “You can open doors for me”

Resident 2: (person with dementia) “*And you can talk for me*”

Resident 1: “And I can talk for you, right (laugh), you can pick things up for me that I can’t reach down for...”

Our study demonstrates the value of good quality extra care housing and shows that it can support people with dementia to live independently in a community setting for as long as people without memory problems.

This study shows that the extra care housing courts included in the research are mainly operating as a replacement for residential care. It clearly improves the range of housing options for people with dementia who would previously have had no alternative other than moving into nursing or residential care homes.

Given the high dependency profile and complex health needs of many residents, the door is open for all stakeholders involved in the delivery of extra care to maximise the preventative role of extra care housing. It is timely that this report is being published shortly after the publication of the government’s new vision for health and social care services.



Opening doors to independence – A longitudinal study exploring the contribution of extra care housing to the care and support of older people with dementia.

Price £25 including postage and packing

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