What can models of 'extra care' housing offer to older people with dementia?

A broad definition of extra care housing is 'specially designed or adapted housing in which varying amounts of care and support can be offered and where some services and facilities are shared'. Government policy promotes 'extra care' housing, although currently it is only a small proportion of total provision and there are debates about its potential to completely replace residential care. This OutLine explores the evidence around options that involve a person with dementia (sometimes with a spouse or family member) moving from their own home into other accommodation.

What are the key pointers to Extra Care Housing?

- Living **at** home – not **in** a home
- Having one's own front door
- Flexible care based on individual need
- Opportunity to rebuild or maintain independent living skills
- Accessible buildings and telecare
- A real community – and benefits accessible to the wider community

(see The Extra Care Housing Toolkit CSIP www.cat.csip.org.uk/housing)

What are the different types of extra care?

Different types are still evolving. They include:

- Continuing care communities/retirement villages
- Purpose built, with or without community resources
- Remodelled from existing sheltered housing or care home
- Housing 'linked' to a care home
- Specialised housing - grouped in a wing or cluster of a larger development or stand-alone
- Small independent living houses - with shared living space
- Core and cluster - central core building, dispersed housing units (co-located or 'virtual' across a locality)

(see also housinglin@cat.csip.org.uk and Cox, 2006)

Is extra care an option for people with dementia?

Dementia is an umbrella term for many different chronic and usually progressive disorders, the most common being Alzheimer's disease, vascular dementia, dementia with Lewy bodies and fronto-temporal dementia. Dementia is also higher risk for people with learning disabilities, Parkinson's disease and alcohol related brain damage. People can have more than one type of dementia. The process is different for each person, but usually involves reduced abilities to understand, remember, communicate and reason. Memory loss is often, but not always, the first sign of dementia. Older people often have other physical and mental health conditions as well as dementia. The words mild, moderate and severe are often used to describe the severity of symptoms and should involve some form of screening and diagnosis (NICE, 2006). Some people may not receive a formal diagnosis.

Person-centred, individualised care and support is the key to maximise the potential of the person with dementia, support family carers, prevent avoidable deterioration and improve quality of life (NICE, 2006). Some people already have a diagnosis of dementia when they move in to extra care housing; often, the condition only becomes apparent after a period of time.

Housing and dementia

Serious gaps exist in the research on housing and dementia. Multi-site studies and comparisons between specialist and non-specialist (integrated) approaches are lacking (O'Malley and Croucher, 2005). One of the most under-investigated issues is whether or not to 'mix' people with dementia with others who do not have dementia. Especially relevant are the multiple exclusions experienced by people with dementia as well as the fear and stigma surrounding dementia.

A review of housing with care in later life (Croucher, Hicks and Jackson, 2006) confirmed that people with cognitive impairment and dementia are often on the margins of social groups and networks. The review (mainly of non specialist housing) found concerns around balancing the needs of people with dementia against those of other residents.

Retirement villages/continuing care retirement communities

A recent review (Croucher, 2006) found that these models expand choice in living arrangements, offer decent age appropriate housing, and assist health and social care providers to deliver community services more effectively and efficiently. Residents with dementia, however, were said to present particular challenges. One evaluation suggested that people with dementia created distress and anxiety to fellow residents. In response the provider invested considerably in additional dementia services to provide better support. The reviewer concludes that more studies are needed to fully evaluate the model with respect to outcomes for people with dementia; in particular to compare outcomes in terms of residents' quality of life, health status or impact on services.

Encouraging findings - Housing 21 extra care

A recent study (Vallelly et al, 2006) looked at what happened to people with dementia in Housing 21 extra care courts over a three year period. Overall, the study demonstrates the value of good quality extra care housing that supports the majority of older people with dementia to live independent lives in the

community for almost as long as people without memory problems (around two years). Many families continued to visit frequently and in some cases relationships were said to have 'improved'.

A 'home for life' was possible for about 50% of tenants with dementia, although some did move on to other settings. Risk, challenging behaviours, conflict with staff and other residents often contributed to such a move, usually to a nursing home.

Is it possible to compare the specialist 'cluster' model and the integrated models?

All of the fifteen Housing 21 schemes, except one, were 'integrated', with people with dementia living alongside others without dementia. Positive findings from the integrated courts included friendships being established and increased understanding and tolerance by other residents. However, there were a few reports of people with dementia being discriminated against by other residents.

The only site with 'specialist 'provision was an extra care development that had a 'cluster' of eight flats for people with dementia in one area of the court, with its own corridor, and separate lounge. This showed:

- specialist care and support targeted on people with higher levels of need
- fewer people moved on to other care settings
- most residents had frequent orientation problems but 'wandering' behaviour was less problematic.

The report makes criticisms about this 'specialisation option', especially with regard to:

- deciding who is most suitable (partly through lack of information on referral)
- problems with accommodating couples where one did not have dementia.
- deployment of specialist staff due to the high numbers of people with memory problems in the remaining flats.

Much more information on quality of life and outcomes in a larger and more balanced sample of housing types is necessary before conclusions can be drawn about the respective advantages or disadvantages of the specialist cluster as against the integrated model.

Dementia and design

All the courts in the study had flats on two floors with lifts. Interestingly more than half of those who moved to other settings had lived on upper floors. The principles and features of dementia friendly design (Judd, 1998) were incorporated variously in different courts. The study found it difficult to identify which orientation aids worked best and suggested more work is needed to identify those that impact on orientation. Design, layout and proximity affects access to shared facilities such as communal lounges, restaurant, day centres and other facilities. Access to gardens and outdoor environments are also important for people with dementia.

There is a developing literature on the impact of design on quality of life and other outcomes (Day, Carreon and Stump, 2000). Further work is needed to examine the impact of different design approaches and features on the way that residents, staff and other people use them in practice (Calkins, 2001).

Quality of life - balance between independence and social isolation?

Reducing social isolation and improving the quality of life of residents are key principles of extra care provision (Croucher, Hicks and Jackson, 2006). The Housing 21 study confirmed that independence is very important to people with dementia - but that getting the balance right between independence and social isolation can be a challenge. Expectations of users and carers are that extra care housing will offer company and access to stimulating activities and interests – often with other people.

Some people with dementia, especially without family member involvement relied heavily on staff to for access to social activities, neighbours and the wider community. This was often not available due to staff and resource pressure. Having their own flats made some people more isolated though others enjoyed time alone in their own private space.

What elements contribute to effective extra care?

The Housing 21 study identifies the following key drivers:

- integrated local strategies for housing, health , social care and support
- interdisciplinary working that is central to assessment, care planning, provision of services and review
- agreed arrangements for tenants to receive timely and appropriate community health services - both physical and mental health services
- flexibility and continuity in care and support staff
- accessible and welcoming opportunities for stimulating activities and social interaction
- involvement in preparation, planning and buying of meals, as well as facilities for communal dining
- staff with specific training about dementia, especially how to respond appropriately to behaviour that challenges services
- greater use of appropriate assistive technology and telecare
- information and awareness raising about dementia with other tenants and families
- promoting links with the wider community.

Is specialist extra care housing the answer?

There is limited research in the UK in respect to the effectiveness and outcomes of specialist extra care for people with dementia, even though some, such as the independent living houses managed by the Dementia Care Initiative (see Cox, 2006) have been operating effectively for some considerable time. Some commentaries (Leichsenring and Strumpel, 1998) based on action research in a number of European countries point to the benefits of living in smaller, more homely settings: specially trained staff, maximising orientation skills, familiarity and ordinary activities, more domestic/homely environment, and close involvement of families.

These approaches continue the tradition of shared housing, with aspects of group living that offer the potential for more companionship and social interaction in an unstructured way in homely environments. These more domestic settings can also integrate dementia friendly design features, with the advantage of visual accessibility and shorter distances, usually on the one level, and easy access to outside space.

An evaluation of a small scale specialist scheme for eight people with dementia (Scott, 2005) offers some useful findings. This development provided a good quality of life for residents - accommodation on a human scale and the benefits were social inclusion, improved skills, flexible person-centred care and the promotion of activity and stimulation. It also offered an alternative for some people who would previously have moved to a care home. Issues remained as to who is best suited to such provision and how to provide appropriate external support.

A larger development by the same organisation (MHA) offers specialist and non specialist units on the same site with 45 non specialist flats, 20 one bed flats for people with dementia, a resource centre providing day care for up to 20 people, and five intermediate care flats. The tenants in the specialist housing have high care needs, with some receiving up to 30 hours per week. All have a diagnosis of dementia.

The evaluation by Dementia North for MHA (see www.mha.org.uk) did not seek to measure outcomes, but early findings suggest that the specialist housing provides good quality specialist support for people with dementia and highly valued individualised care, choice and empowerment. Some tenants receive levels of care comparable to that in a care home, and family members and residents had a sense of security over staff cover and assistive technology. Community life is generally inclusive and the needs of the person with dementia taken into account. Again there were some concerns about layout (long corridors) and difficulties in accessing communal facilities.

It is clear that specialist developments are liked by residents and family members, and that for some commissioners they provide a useful option in the network of local dementia services.

There are some indications that specialist approaches may be able to sustain people longer in an independent setting, but further work is required to explore the implications for quality of life, housing care and support services, and costs. This may depend on better integration of services (CSIP, 2005).

Conclusion

There are very positive messages about extra care housing offering a good quality of life. It appears to offer for some people with dementia, an alternative, more independent lifestyle than is possible in a care home. There are still many gaps in our knowledge. More work is needed on comparisons between the housing, design and care components of the different types of specialist and mixed/integrated developments. More rigorous evidence is needed about outcomes, but there is little consensus about how to collect dementia specific data especially with regard to resident characteristics.

More studies are needed on:

- responding to diversity, for example BME communities
- cost effectiveness (ongoing work by PSSRU should assist www.pssru.ac.uk/research
- specific aspects of design and living environment and impact on outcomes
- impact of telecare in different models – for example the idea of the 'virtual' extra care community
- access to health care and palliative care to prevent unnecessary moves.

The 'extra care' concept should be able to deliver individualised outcomes within the new personalisation agenda that highlights expanded choice,

enhanced voice and partnership provision. Translating such vision into reality demands concerted action and an eye to innovation and creativity to avoid a drift to institutionalisation. There is always the risk of marginalising people with dementia unless their voices are heard and preferences and potential recognised.

Written for **research** *in* **practice** *for* **ADULTS** by Sylvia Cox, independent consultant

References

Calkins M P (2001) The physical and social environment of the person with Alzheimer's disease, *Aging and Mental Health*, 5, supplement 2, 74-78

Cox S (2006) *Home solutions 2: Housing, care and support for people with dementia,* Dementia Services Development Centre, University of Stirling

CSIP (2005) *Everybody's Business: Integrated mental health services for older adults*

Croucher K (2006) *Making the case for retirement villages*, Joseph Rowntree Foundation

Croucher K, Hicks L and Jackson K (2006) *Housing with care for later life: a literature review,* Joseph Rowntree Foundation

Day K, Carreon D and Stump C (2000) The therapeutic design of environments for people with dementia: a review of the empirical research, *Gerontologist,* 40, 397-416

Judd S, Marshall M, Phippen P (1998) *Design for Dementia*, London, Hawker Publications

Leichsenring K and Strumpel C (1998) *The use of small housing units for older persons suffering from dementia*, European Centre for Social Welfare Policy and Research, Vienna

NICE and SCIE (2006) *Dementia: Supporting people with dementia and their carers in health and social care*

O' Malley L and Croucher K (2005) Housing and dementia care: A scoping review of the literature, *Health and Social Care in the Community*, 13, 570- 577

Scott J (2005) Portland House: an extra care development for people with dementia, *Signpost,* 10(2), 17-22

Vallelly S, Evans S, Fear T, and Means R (2006) *Opening doors to independence: A longitudinal study exploring the contribution of extra care housing to the care and support of people with dementia* London Housing 21 (summary available at www.housing21.co.uk)

To find out how to become a Partner in **research** *in* **practice** *for* **ADULTS**
please contact Alison Petch alison@ripfa.org.uk 01803 869754
or write to us at Blacklers, Park Road, Dartington, Totnes, Devon, TQ9 6EQ

© **research** *in* **practice** *for* **ADULTS** April 2007

a department of The Dartington Hall Trust
a company limited by guarantee registered in England and as a charity
Registered office: The Elmhirst Centre, Dartington Hall, Totnes, Devon TQ9 6EL