

The role of housing in addressing the needs of people with dementia

Key findings from a three year study evaluating the contribution that extra care housing can make to the care and support of people with dementia

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Key findings from “Opening Doors to Independence”

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About Housing 21

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- A national specialist working with older people across housing, care and support services
- 14,000 homes nation-wide in sheltered and extra care courts
- National home care provider
- Acknowledged leader in building new extra care courts

Housing Corporation programme £40 million/320 new homes

Department of Health programme £40 million/344 new homes

Our Interest in Dementia

- **Currently over 750,000 people in the UK have dementia.**
- **An ageing population: by 2031 there will be 15 million people over state retirement age**
- **By 2050 there will be 1.8 million people with dementia**
- **We aspire to provide a 'Home for Life'**
- **Dementia is a key challenge for us and central to all our work**

Key features of extra care housing:

- On-site care team (24 hour cover)
- Flexible care packages tailored to people's individual needs
- Enabling care ethos
- Special design features to assist orientation
- Individual flats with own front doors



3 year tracking study funded by the Housing Corporation and in partnership with the University of the West of England, Bristol (UWE) and Dementia Voice

AIMS:

- Evaluate the contribution extra care can make to the long term care and support of older people
- Limitations and challenges
- Good practice and recommendations
- Capture views of older people with dementia, relatives and staff

Key Findings

Opening Doors to Independence

- **Extra care is offering a good quality of life to the majority of residents with dementia**
- **Benefits of extra care overwhelmingly endorsed by families and older people themselves**
- **The flexibility of care and support is a key strength of extra care housing**
- **Assistive technology where in use can be very effective in enabling frail older people to maintain their independence**
- **Dementia alone does not have a negative impact on potential to live independently in extra care housing**
- **Balancing independence and isolation is key to managing extra care schemes successfully**

What residents with dementia liked about Extra Care

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- Older people with dementia were able to express their views
- Extra care meets many of their aspirations

They particularly liked:

- *peace of mind and security*
- *independence and privacy of own flat*
- *alarm system*
- *eating in restaurant*
- *positive relationships with carers - particularly where we were able to achieve continuity*
- *“still part of the community”: involving relatives & friends*

“It’s not living with your family but it’s the next best thing”

Can Extra Care offer a Home for Life to older people with Dementia?

- Residents move in 84+ years old & high dependency needs (10 hours+)
- Significant other health problems & care hours generally increased over time
- *“Added housing years”*: 16 residents have been living there over whole course of study - average residence period: 3.6 years
- 45 people died or moved on over the course of the study
- 50% moved to nursing care
- Repeated use of emergency alarm, distress, conflict and “challenging behaviours” were identified by staff as triggers for move on
- Little evidence of “wandering” as a risk factor

End of life care issues

- **Most people who died (62%) were in hospital at time of death**
- **90% of the people who died had other health conditions as well as dementia when they moved into extra care housing**
- **Most hospital admissions following acute episodes just a few days prior to death**
- **GPs and district nurses tend to be less involved with the care of older people with dementia than those dying from other conditions**

- The complexity of long term care funding mitigates against our ability to support people to die at home
- An integrated strategy that involves health care has a positive impact on residents in extra care but it is not the norm.
- Extra care could provide an environment for a radical reassessment of the care of older people with complex health needs.



Case study – issues and challenges

- An 87 year old woman had moved into extra care having been diagnosed with dementia prior to the move. The extra care housing scheme was closer to her family. More recently she was diagnosed as terminally ill from cancer.
- The social services authority who funded her care wanted her to be moved to a nursing environment as she would qualify for 'continuing care'.
- Her GP, the scheme manager and her family all worked together to support her in extra care as this was her wish. Though her physical health declined rapidly and her care package increased, her mental state and quality of life had improved since she moved in. She displayed no awareness of her illness and became distressed if she had to go out.
- The scheme manager had organised that Macmillan nurses were on standby to provide specialist palliative care in the latter stages of her illness.

“Extra care with the right ingredients can offer older people with dementia both security and independence, and above all a good quality of life”

- Flexible care and support
- A stimulating environment
- Specialist training and support for staff
- Integrated strategies for housing, health and social care
- Access to health care

- End of life / palliative care training for care staff
- Dementia awareness training for all care staff
- Improve engagement of primary health care – most often this is through district nursing support.
- Making the links – active engagement with community & specialist support sources, local voluntary organisations
- More people should be enabled to die in their home if this is their choice
- More respite support for carers and family members

- The idea that people with dementia should be in a care home is increasingly an outmoded assumption.
- Many residents in extra care housing have complex health needs and most of those health needs are being met within the housing setting.
- Research will shortly be underway to evaluate how well 'end of life' care can be delivered in extra care housing.

REFERENCES & CONTACT DETAILS:

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Housing Learning and Improvement Network (LIN) -

<http://www.changeagentteam.org.uk/index.cfm?pid=10>