

Housing Learning & Improvement Network

Supporting People with Dementia in Extra Care Housing: an introduction to the issues

This fact sheet provides an overview of developing and managing Extra Care Housing for people with dementia. It accompanies a video on Extra Care Housing and Dementia available on CD-ROM from the Housing Learning & Improvement Network at housinglin@e-a-c.demon.co.uk.

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The Health and Social Care Change Agent Team (CAT) was created by the Department of Health to improve hospital and social care associated arrangements. The Housing Learning & Improvement Network, a section of the CAT, is devoted to housing based models of care and support for adults.



Other Housing LIN publications available in this format:

- Factsheet no.1: **Extra Care Housing - What is it?** (28.07.2003 updated August 2004)
- Factsheet no.2: **Commissioning and Funding Extra Care Housing** (28.07.2003 updated August 2004)
- Factsheet no.3: **New Provisions for Older People with Learning Disabilities** (23.12.2003 updated August 2004)
- Factsheet no.4: **Models of Extra Care Housing and Retirement Communities** (04.01.2004 updated August 2004)
- Factsheet no.5: **Assistive Technology in Extra Care Housing** (20.02.2004 updated August 2004)
- Factsheet no.6: **Design Principles for Extra Care** (26.07.2004)
- Factsheet no.7: **Private Sector Provision of Extra Care Housing** (21.07.2004)
- Factsheet no.8: **User Involvement in Extra Care Housing** (24.08.2004)
- Factsheet no.9: **Workforce Issues in Extra Care Housing** (04.01.2005)
- Factsheet no.10: **Refurbishing or remodelling sheltered housing: a checklist for developing Extra Care** (04.01.2005)
- Factsheet no.11: **An Introduction to Extra Care Housing and Intermediate Care** (04.01.2005)
- Factsheet no.12: **An Introduction to Extra Care Housing in Rural Areas**(04.01.2005)
- Factsheet no.13: **Eco Housing: Taking Extra Care with environmentally friendly design** (04.01.2005)
- Case Study Report: **Achieving Success in the Development of Extra Care Schemes for Older People** (July 2004)

Supporting people with dementia in Extra Care Housing

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1. Introduction

Dementia in all its forms affects 1 in 20 people over the age of 65. One quarter of people over 85 develop dementia (1). With an ageing population, it is likely that these numbers will increase. Arguably, we are moving from a world dominated about concerns related to chronic and neurological diseases to treating and supporting people in a person-centred way. The emphasis is on taking a “whole system” approach to health, housing and personal services.

For people living with dementia the most fundamental housing issue is that which faces everyone who has to consider their housing situation in the light of changing circumstances, or the prospect of changing circumstances: “should I stay or should I go?” Of course, how long it will be possible to stay, and when and where to move are not questions unique to those living with dementia. However, a key question for an older person with dementia and for planners and commissioners of provision for older people is the extent to which Extra Care Housing (ECH) can provide an appropriate housing option.

Whilst most older people say that they would rather avoid the need for residential care, it has often been seen as the only option for people with dementia. Although space standards and arrangements to preserve privacy, independence and autonomy have improved there is no disguising the reality that, in these circumstances, the quality of accommodation is being traded for access to care.

Many sheltered housing schemes are able to accommodate existing residents who exhibit symptoms of dementia. However, most will find difficulty in successfully integrating new arrivals with pre-existing conditions (2). As a result, access to sheltered housing for a person exhibiting more than the mildest forms of dementia is likely to be highly problematic as many providers, both local authority and housing association, have selection and allocation policies that screen out people with dementia.

2. Policy issues and connections

There is no single path to the appropriate answer for someone deciding on their accommodation options whilst living with dementia. This will require a commitment on the part of commissioners and providers to develop housing based models of specialised accommodation and care. Local authorities and their health partners will need to look at the longer term and make an assessment of the likely demographic change and changing dependency levels across the area.

Commissioners and providers of Extra Care Housing need to be aware of the Mental Capacity Bill and the Mental Health Act. At the time of writing this fact sheet, the Mental Capacity Bill has had its third reading. There will be new

legislation which will give new legal rights to people, including those with dementia and their carers. The Bill will enable people with dementia to be more involved in decisions about their health and personal welfare.

Other frameworks for supporting people with dementia may be found in *Preparing Older People's Housing Strategies*, ODPM/DH (2003) and *Developing and Implementing Local Extra Care Housing Strategies*, DH (2004).

In addition, ECH also creates a new set of expectations and relationships between the particular resident(s), the provider and their partners. These expectations, in what is still a relatively new model of housing, need to be reflected in the Single Assessment Process and the impact of Direct Payments so that it can accurately reflect needs in the context of changed aspirations and choices of provision.

The National Service Framework for Older People provides an opportunity for health, housing and social care staff to establish effective joint working. It stresses the importance of early detection and diagnosis of people with dementia and the actioning of changes within the home and the availability of alternatives to residential care. This will require Social Services and PCTs to work together to develop seamless services, single assessment processes and a system of integrated care (3).

It is estimated that over two-thirds of people discharged from hospital have a mental health problem (4). Indeed this figure includes people with dementia but their specific needs are often little understood.

The Community Care (Delayed Discharges) Act 2003 has provided new impetus here. The Department of Health is concerned that people with dementia should therefore only be admitted to acute wards when there is nowhere else appropriate to manage their physical health problems. In addition, they should be returned to their usual place of residence as quickly as possible (5).

3. What can Extra Care Housing Provide

Even where someone does not encounter resistance this is not necessarily a suitable environment where the design may include long dimly lit corridors and large communal areas. Whilst some conventional sheltered housing has been remodelled with enhanced facilities and services these are primarily directed at older people experiencing physical frailty rather than cognitive impairment.

ECH schemes, whilst carrying forward the sheltered housing concept of independent units of accommodation, provide a more systematic approach to increasing frailty in general and cognitive impairment in particular.

There is some debate about whether people with dementia should be able to live anywhere within an extra care scheme or whether there need to be special wings or areas. Some argue that people with dementia should be fully integrated as separating them reinforces discrimination. Anyone whose cognitive impairment was not very advanced, they argue, would be unwilling to move into a specialist unit and those whose cognitive impairment was severe would need a high level of care and have a very limited capacity to take advantage of the facilities offered by the scheme (6, 7).

Others advocate specialised units that recognise the rather different needs of people with dementia. These will generally group the accommodation in small clusters and the provision of communal facilities within those sub-units. The overall design will allow for circulation and whilst providing for security and containment is designed to allow the highest degree of free circulation within that.

Certainly, what most people seem to be able to agree on is that ECH is not really appropriate for people entering the scheme with dementia in its advanced stages. Extra Care housing with its 24 hour care cover offers the potential to meet the needs of people with dementia which less supported forms of housing cannot (8).

4. Design principles and Dementia

Judd S, Marshall M and Phippen P in *Design for Dementia* (9) show several examples of good and clear design. From this they have extracted the following two key principles that constitute good design:

i) The consensus on principles of design is that *the design* should:

- compensate for disability;
- maximise independence;
- enhance self-esteem and confidence;
- demonstrate care for staff;
- be orientating and understandable;
- reinforce personal identity;
- welcome relatives and the local community;
- allow control of stimuli.

ii) The consensus on *design features* includes:

- Small size;
- Familiar, domestic and homely in style;
- Plenty of scope for ordinary activities;
- Unobtrusive concern for safety;
- Different rooms for different functions;
- Age appropriate furniture and fittings;

- Safe outside space;
- Single rooms big enough for lots of personal belongings;
- Good signage and multiple cues where possible e.g. sight, smell and sound;
- Use of objects rather than colour for orientation;
- Enhancement of visual access;
- Controlled stimuli, especially noise.

A full checklist first developed by Sue Garwood and Siobhan Moore at Hanover Housing Association is available at Annex 1. Also see Factsheet 6 on design published by Housing LIN at www.changeagentteam.org.uk/housing

5. Good practice examples

There have been a number of schemes that have sought to maximise independent living for people with dementia within extra care housing. These tend to focus on specific aspects of design or on the use of assistive technology. The following examples provide a good indication of the current range of responses.

Assistive Technology in Dementia Care, Eastleigh

Fernhill Care Ltd (a subsidiary of **Atlantic Housing Group**) have developed a scheme designed to maximise independence for older people with dementia. Rowan Court in Eastleigh is home to 21 people with dementia, each with their own flat. A central feature of the scheme is the hard wiring of the building to provide for a wide range of assisted technology. All flats have a heat sensor and a flood detector. Cabling is in place to add extra functions on an 'as required' basis, following individual assessment of need.

So far the scheme covers individual call systems as well as heat detectors for each flat and there are flood detectors in the bathrooms for identified residents. The scheme is currently using a bed occupancy sensor that signals when a resident has been out of bed for more than a minute and wandering sensors that indicate when doors to communal areas are open etc. A double door entry system is controlled by staff to prevent wandering and one of the two large lounges opens onto an enclosed garden. Other sensors such as smoke detectors, carbon monoxide sensors and fall detectors are available. However, technology is not seen as substitute for staffing and a scheme manager is on-call through 24 hours, there are five staff available during the day, four in the evenings and one on awake duty at night. Additional support could be available from the neighbouring extra-care facility if needed. (For further information see Housing LIN Case Study No. 3).

Supporting Independence at home, Woodbridge, Suffolk

Deben View is a scheme in Woodbridge, Suffolk which resulted from a partnership between **Orwell Housing Association, Suffolk District Council and Suffolk Social Services**.

There are 32 self-contained one and two bedroom flats each with its own front door, bedroom(s), lounge, kitchen and shower room (including WC). In one wing, eight of the flats provide an extra care service either for people suffering from dementia or those with a functional mental health problem.

The eight extra care flats are built to the same design as the rest of the scheme. In addition, these flats have been installed with assistive technology and motion detectors. Residents can freely move from the wing to other parts of the scheme and an enclosed garden – although there are alarms on the doors.

The Extra Care has a higher staff ratio with one staff member per four residents on each shift. Residents with some form of cognitive impairment are encouraged to have the same expectations as other residents. Through careful care mapping and Lifestyle Agreements that are developed with each resident they are able to build up a picture of someone's needs and respond appropriately.

Seven Oaks Dementia Care Unit, Northern Ireland

The Seven Oaks Scheme in Derry, Northern Ireland, managed by **Fold Housing Association**, is an extra care purpose designed dementia care unit. It currently has 30 residents each with their own en-suite bedroom and offers:

- i) A high dependency area that offers support for problems with wandering and incontinence;
- ii) A homely environment for people with mild dementia;
- iii) Five two bedroom bungalows that enable couples to continue living together when dementia might otherwise force a separation; and
- iv) A re-ablement service that works with people to return to their homes after a hospital stay.

The layout of the scheme is based on the town of Derry and uses familiar landmarks and street names to facilitate navigation. The unit is built around a central courtyard garden with circular corridors leading around it. As well as individual rooms with en-suite bathrooms, there are several shared sitting rooms, dining rooms and a pub. One street has shops including a grocers, hairdressers and a chemist often using the names of streets in Derry. The decoration is 'homely' and old items such as manual sewing machines and gramophones are used to provide a sense of familiarity.

Smart housing design for people with dementia, Gloucester

In partnership with **Housing 21** and the **Bath Institute of Medical Engineering (BIME)**, **Dementia Voice** has converted an ordinary 3-bedroomed house into a dementia-friendly environment that demonstrates how technology and design can assist people with dementia to retain independence, especially in their own homes.

The house has been decorated to support people with dementia with orientation difficulties, utilising colour and tone contrast and clear signage as memory aids. In addition, it has been fitted with technology, systems and features designed to provide a greater independence and assist daily living for people with dementia. For example, using a combination of communication, monitoring and technology, bath water levels can be monitored. On reaching a pre-determined level, the user will be reminded to turn off the water. If the user fails to respond to reminders, technology will intervene and the water will stop. The mechanism for turning off the water is designed to ensure that it does not cause further confusion to the user by leaving the tap apparently turned off. The bath can be topped up by the user by simply turning the tap up again.

6. Key learning points

- ECH is preferable to institutional care for someone who develops dementia provided that higher levels of care or necessary specialist input is available and, where necessary, funded by social services. If someone moves in early in their dementia they may, with appropriate support be able to live there for life.
- People should move into ECH as early as possible whilst they still have some understanding of what they are entering into, still have the capacity to develop relationships and are able to adapt to new surroundings - albeit with support. Location within a neighbourhood in which the person with dementia is well known and is likely to be cared for or returned to home is a significant benefit.
- It is helpful if people have early specialist assessments and diagnosis so that they can plan and prepare for the future. It is preferable to get as much of their life story, likes and dislikes from the individual themselves rather than from friends and family.
- It is important to optimise familiarity with the environment. A well-designed and safe environment has benefits for the person with dementia and their carers. Small schemes, that will support people living with dementia, with or without a carer, in a flexible way, offer positive directions for future development (10).

- There is a wide range of assisted technology and telecare products on the market, including door sensors or wandering bracelets which, with appropriate protocols and ethically, and proper staffing, can replace closed doors. These technologies can play an important part but it is the interaction with staff and other people that 'unlocks' someone's skills and abilities. (For further details visit the Integrated Community Equipment Services website referenced below).
- Agencies and professionals involved in delivering Supporting People funded services will need to understand the positive options for supporting people with dementia within an ECH scheme and how they may be accessed. It is important that providers are allowed to assess the levels of need that a scheme can cope with – there is an understandable desire on the part of commissioners to want to increase levels of dependency in schemes to get "best value". The trouble is that this may impose more pressures on schemes than they can sustain.
- There is a need for better dementia awareness training and education to be provided for housing and care staff, including person-centred training on individual care and support plans. In addition, to develop joint training with primary care and hospital staff to enable early diagnosis of dementia and work with individuals and support carers on dementia care pathways (11).
- Involve people with dementia and their carers at an early stage in making decisions that affect their every day lives. There should be access to accessible information and support to enable choices to be made and to provide guidance. Where appropriate staff should signpost to advocacy services e.g., in relation to issues affecting mental capacity.

7. References

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- 2 Kitwood T et al (1995). *Brighter Futures: a report on research into provision for persons with dementia in residential homes, nursing homes and sheltered housing*. Anchor Trust, Oxford
- 3 Department of Health (2001), *National Service Framework for Older People*. DH, London
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- 6 Garwood, S (2004) Presentation to Worcestershire County Council Extra Care Conference July 2004. www.changeagentteam.org.uk/housing

- 7 McDonald A & Curtis, J. (2001). *Not Alone – A good practice guide to working with people with dementia in sheltered housing*. Housing Corporation & Anchor Trust: Oxford.
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- 10 Leichensring K & Strumpel C. (1998). *The Use of Small Housing Units for Older Persons Suffering From Dementia*. European Centre for Social Welfare Policy and Research. Vienna.
11. Macdonald A (2001), *Not Alone: a development pack for supporting people with dementia in sheltered housing*. Housing Corporation & Anchor Trust. Oxford

8. Other useful reading

Brooks L, Abarino T and Smith M (2003). *Care and support in very sheltered housing*. Counsel & Care. London

Cox S (1998). *Home Solutions: housing and support for people with dementia*. Housing Association Charitable Trust, London

Housing LIN (forthcoming). *An introduction to Extra Care Housing for people with functional mental health problems*. www.changeagentteam.org.uk/housing

Marshall M ed (1997). *State of the art in dementia care*. Centre for Policy on Ageing, London

Suffolk County Council (2004). *The Suffolk very sheltered housing design and management guide*. Available at www.changeagentteam.org.uk/housing

Vallelly S (forthcoming longitudinal survey). Housing 21, Beaconsfield

9. Useful Contacts

Alzheimer's Society

The Alzheimer's Society is the UK's leading care and research charity in for people with dementia, their families and carers. Further recommended reading and Information about aids and adaptations, architecture and housing can be downloaded from their website at www.alzheimers.org.uk

Counsel & Care

Counsel and Care is a charity giving advice and information to older people, their relatives and carers across the UK. They have a number of useful factsheets and publications at www.counselandcare.org.uk

Dementia Services Development Centres

A Dementia Services Development Centre (DSDC) is an agency or organisation which exists to provide services and information in a specified geographical area on all aspects of dementia and dementia service provision to commissioners, service providers and policy makers. Many of them are also able to offer specialist training. For details of your local DSDC visit www.dementia.stir.ac.uk/network/network.htm

Integrating Community Equipment Service (ICES)

ICES is a Department of Health funded initiative across health and social care to develop integrated community equipment services in England. For up-to-date information on assistive technology and community equipment visit www.icesdoh.org

National Institute for Mental Health

The National Institute for Mental Health in England (NIMHE) manages a regional network of service improvement and development centres to support people involved in mental health and people who use services. For details of your local NIMHE centre, visit www.nimhe.gov.uk

A CHECKLIST OF FEATURES FOR DEMENTIA-FRIENDLY DESIGN

Outside:

- Secure boundaries so that it is safe to wander, but perimeter to be as unobstructive as possible e.g., hedging rather than fence
- Circular paths with interesting features along them to stimulate interest and aid orientation
- Wide field of vision without major visual obstacles to allow staff observation
- Planting should be sensory & tactile planting (avoid dangerous plants)
- Design should preferably include a working area including potting/greenhouse and raised planters and traditional washing lines

Indoors:

- Use of wall colouring to aid orientation should be neutral and **not** patterned. Colour changes should be obvious rather than subtle
- Conspicuous colours on doors needing to be identified by person with dementia e.g., WC doors should be same colour and have appropriate signage
- All doors **not** needing to provide access to residents e.g., sluice rooms to be the same colour as walls to merge into background
- Flat doors to be denoted through pictures, colours and/or signs as personal to the occupant as possible e.g., picture of the occupant/tools used in former trade
- Use of symbols in addition to any signs to be at eye level
- Use of distinctive pictures, artefacts, bay windows, activity alcoves etc to provide unique landmarks to aid orientation and to provide point(s) of interest
- To prevent the wanderer from exhausting themselves or becoming frustrated, common areas should be open plan (or easily viewed through maximising windows internally and externally) as possible.
- Minimal use of corridors as these increase disorientation, where possible should be wide to minimise feeling restricted
- Preferably there should be no corridor ends e.g., there should be continuous circular path (both internal and external)
- Increased lighting in activity areas, aiding interpretation, as well as maximum use of natural light to differentiate between day and night
- Reduce as far as possible echoes and features that cause sound disorientation
- Floor fittings should be plain (heavy patterns cause confusion) and non-slip. Textile and colour should be consistent as possible throughout scheme with flatted areas and communal areas distinguished by different colour flooring
- Fittings and equipment to be as standard as possible to aid familiarity
- Heavy sprung doors should be avoided
- Windows should allow a good view from seated position
- PIR (infra-red) sensors may be useful in monitoring wandering (often linked to call centre/scheme staff)
- There should be colour contrasted tiles surround bathroom/WC fittings to distinguish depth and location
- It may necessary to hide some control switches e.g., for fridges to remove the temptation to turn everything off (or on such as gas)
- Consideration should be given to lighting or use of light sensor between bedroom and bathroom to aid orientation, especially at night