

Living beyond dementia

a guide to dementia and Housing with Care

H | D | R | C

Housing and dementia research consortium

Foreword: Housing and Care that works

As more of us live to a greater age, many more of us also wish to live independently for longer, whatever our physical, mental and emotional needs may be. For individuals living with dementia, independence remains a felt and valued need. Increasing experience and growing evidence shows us that there are effective ways of ensuring that this is maintained.

Housing with Care is an important development that helps those with dementia to live the lives that we would wish them to enjoy. Mounting research suggests not only that people with dementia who live in Housing with Care generally have a good quality of life but that, also, it can deliver prolonged residence in the same home, delaying or even preventing moves to a Care Home.

Based on an extensive review of research published in 2009 by the Housing and Dementia Research Consortium (see p.14), this guide outlines what we know about living with dementia in the Housing with Care setting, and those factors which we believe contribute to making this care that works well. *Living Beyond Dementia* is designed to assist anyone who is thinking about issues relating to housing and dementia – from potential residents and their families to care providers and policy makers. It offers advice, drawn from the 2009 research, about the design and facilities of appropriate Housing with Care as well as the care and support that best enables older people with dementia to live independently. Above all it points to the benefits of a lifestyle that offers the dignity and sense of wellbeing that older people seek.

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What is dementia?

Dementia is an umbrella term, covering a number of conditions that manifest themselves in similar ways. The most common type of dementia is Alzheimer's disease, which accounts for about 69 per cent of all cases.

An individual living with dementia will experience a decline in two or more of the following capacities:

- **memory**
- **generating speech or understanding spoken or written language**
- **capacity to plan, make sound judgments and carry out complex tasks**
- **processing and interpreting visual information**

These impairments will persist over time and be severe enough to interfere with day-to-day life. They may also manifest themselves through disorientation, confusion or forgetfulness, or in particular forms of behaviour (such as walking about, repeated talk or actions).

Some of this behaviour can be very challenging to deal with. Without appropriate stimulation, therapies and/or oversight such behaviour may disrupt the lives of relatives, friends and neighbours. The individual living with dementia may even experience discrimination and social isolation.

Good Housing with Care recognises these challenges and responds with appropriate support, resources and surroundings.

What is Housing with Care?

Housing with Care offers more independent living than that which is possible in a Care Home. The concept goes by different names, including 'Extra Care Housing', 'Very Sheltered Housing' and (especially in the USA) 'Assisted Living'.

Whatever the differences in design, layout and environment, all Housing with Care aspires to deliver an experience of:

living in a self-contained unit (including a bedroom, bathroom, living area and kitchen) within a development that provides flexible person-centred care services with an ethos of homeliness, choice, independence, privacy, and minimising the need to move.

The 'housing and environment' elements of Housing with Care are as important as the care provided there. By being aware of all three factors, Housing with Care expands the range of choices available for older people and for care providers. Together, appropriate housing and round-the-clock-care can support independence. Experience and recorded evidence demonstrates that this is an achievable goal for those with **early to moderate stages of dementia.**

The ability to promote and retain a person's independence decreases as dementia and/or other health and care needs increase. Nevertheless, by enabling individuals to live in a community setting and retain their independence for as long as possible, Housing with Care offers a realistic goal of prolonged residence in the same home, delaying or even preventing moves to nursing care.

Housing with Care: what to expect?

- **self-contained accommodation, usually flats or bungalows**
- **communal facilities such as lounges, restaurant, communal kitchen, hairdressing salon**
- **tenants with a legal right to occupy the property**
- **provision of individualised packages of care if required**
- **catering facilities providing meals**
- **care staff and support available round the clock**

Three key principles

At its best, Housing with Care aims to enhance an individual's experience of independence, empowerment and accessibility.

*Independence –
Doing things for yourself*

*Empowerment –
Retaining the ability to make choices*

*Accessibility –
Equal rights and opportunities*

A wide range of factors contribute to a resident feeling independent and empowered, as well as able to access all areas of a development. Some of these are noted below in the section headed 'What aids success?' (see p.10)

In broad terms, a person's sense of independence and wellbeing is closely related to the quality of care received, relationships enjoyed, and the surrounding environment. These are experienced through some or all of the following:

- the ability to age in a single place that feels like home
- appropriate person-centred care
- meaningful relationships and interaction with other people
- activities that are suited to the individual and which bring pleasure and a sense of accomplishment
- management of pain or discomfort, including incontinence, and of common behaviours such as anger and distress
- homely and easy to understand environments
- appropriate assistive technology that is well explained and is used in accordance with the resident's needs/wishes

Supporting the independence of an individual enhances their personal dignity and improves their quality of life. In addition, appropriate activities have the potential to delay decline in mental and physical function, and increase the length of tenancy for those with dementia in Housing with Care settings.

Independence, empowerment and accessibility – three examples:

If a resident can choose from a range of activities, and whether to be involved or not, their personal dignity is respected.

If a resident is assisted with everyday tasks or enabled to undertake a personal routine, a sense of familiarity may be developed, connecting past with present.

If an environment is pleasant and easy to understand, it is more likely to offer opportunities for residents to improve their mobility and to encourage eating and drinking.

Three essential ingredients

Professionals rate the three most important features of Housing with Care as:

*Flexible care –
responsive to tenants' fluctuating
care needs*

*Self contained dwellings –
control of one's own front door.*

*A 'homely' feel –
living 'at home', not in an institution*

It is clear that people with dementia who live fulfilled lives in Housing with Care developments do so in large part because of the flexible and responsive care and support they receive. This requires staff to have a positive attitude and good understanding about dementia in general and about each individual with dementia. Flexibility will be a mark of the ethos of a development. Those working there will be alert to the risk of loneliness, social isolation and discrimination that some individuals with dementia can experience,

and staff will be able to respond to overcome such possibilities.

A Housing with Care development will reflect the interests and needs of those living in it; it won't have an off-the-shelf feel. The atmosphere and arrangement of communal areas is as important as that of an individual's own flat or bungalow. Housing with Care will have adequate space throughout and within each flat. It will feel welcoming to relatives and friends. As well as giving each resident the dignity marked by his or her own front door, the development will also be designed to facilitate residents to move around with minimal risk.

First questions

Delivering or choosing Housing with Care for individuals living with dementia immediately raises four 'first questions':

Who is it for?

Does size matter?

What are the 'extras' in Housing with Care?

How seamless is your service?

Question 1. Who is it for?

It is vital that all those involved in developing Housing with Care are clear from the outset what they intend to achieve and for whom. This means asking two further questions.

Who should be allocated a property?

There is strong evidence and general agreement that it is not appropriate for people to enter Housing with Care when they already have advanced dementia. (See 'What aids success?' on page 10.)

In addition, high levels of staffing and resources are required to support individuals living with dementia. Inevitably care needs rise as the illness progresses. Is the Housing with Care scheme set up to meet those increased needs while still remaining true to the concept of promoting independence in later life?

To integrate or not to integrate?

Housing with Care may accommodate people with dementia in flats alongside all other tenants. Alternatively, the development may offer a dementia-specialist model of care – either by having one wing or floor that specialises in dementia care or by delivering a dementia-only service.

Existing evidence suggests that fully integrated developments offer benefits for people with dementia through additional opportunities for stimulation, social integration and support from other residents. Residents without dementia may 'feel useful' and enjoy 'looking after' cognitively impaired friends and acquaintances – though, for some, the presence of individuals with dementia can be unpopular and problematic.

Specialist models appear to be liked by residents and their families. It is also worth noting that the advantages of integration diminish over time as the impairments of those living with dementia increase.

Question 2. Does size matter?

There are pros and cons regarding the size of Housing with Care developments.

Larger buildings or layouts are more likely to be able to provide a wider range of amenities and facilities, including leisure and non-care related facilities. They may be better able to accommodate both fit and frail older people and more easily enable the development of a 'vibrant' community. However, an extensive layout can be disorientating and confusing.

On the other hand, smaller developments allow staff to have greater contact with fewer residents and to get to know their personalities, needs and routines more intimately – thus offering the possibility of building a greater sense of community.

Question 3. What are the 'extras' in Housing with Care?

Care for people living with dementia is most successful and sustainable when there is flexibility in the way it is delivered. That means that the staffing and resources required over time must be taken into account when planning the service.

As the symptoms of dementia increase, more care is required and so are more resources. In addition, certain types of behaviours may be very difficult to support, may be more disruptive to other residents, and will be more resource-intensive for the development.

Housing with Care demands extra:

- **staff time**
- **staff training, skills & knowledge**
- **supervision and support of staff**
- **assessment and reassessment procedures for residents**
- **specialised activities and resources**
- **procedures to address behavioural symptoms**
- **procedures to support residents moving in and moving out**

Question 4. How seamless is your service?

Integrated local strategies for housing, health and social care services, including appropriate support from community health and specialist care services, leads to a better quality of care and life experience for residents with dementia.

The ability of Housing with Care to support people with high levels of need depends on the availability of local services (such as community nursing), which in turn depends on local practices and national strategies for older people's services. Such a 'seamless service' also demands a long term funding strategy.

This is true at the level of the Housing with Care scheme as a whole, but also at the level of individual care where clear accountability and sharing of information is essential.

What aids success?

There is mounting evidence that people with dementia living in Housing with Care tend to have a good quality of life. But what makes it successful and who is involved? Studies consistently highlight the importance of:

- **person-centred care**
- **developing knowledge and expertise in dementia**
- **partnership and joint working**

Success for residents

Person-centred care

Person-centred care is care tailored to the needs, interests and strengths of an individual. Residents expect care staff and support to be available around the clock. They perceive their quality of life as better when members of staff are more involved in planning their care and when they express a positive attitude and good understanding about dementia.

Their dignity and sense of wellbeing is enhanced when staff help them to manage symptoms of dementia, such as incontinence, and common behaviours, such as anger and distress, while recognising them as unique individuals, not a cluster of symptoms.

Timing

There is strong evidence and general agreement that it is not appropriate for people to enter Housing with Care when they already have advanced dementia.

Individuals who move into a scheme early after the diagnosis of dementia still have the understanding and capacity to develop relationships and adapt to new surroundings. Their familiarity with their home means that they are more likely to remain living in the accommodation.

Building design

Communal facilities, such as lounges, a restaurant, a communal kitchen and hairdressing salon, offer both practical support to residents (such as provision of meals) and also enable social interaction, helping build a sense of community.

Adequate spaces for gatherings of both large and small resident groups should be provided.

Effective buildings can help compensate for physical and sensory disability. For individuals living with dementia, effective buildings should be understandable and easy to orientate around. Strategies that assist recognition generally include the use of distinguishing colours, landmarks and signage. Also increasingly popular is the use of portrait-like photographs and personal memorabilia (for example in 'memory boxes') to help residents identify their own front door. These should be well-lit and contain items of special significance.

A number of studies have shown that improved lighting can have wide-ranging benefits, including improvements to appetite, health, and self-confidence, and decreased incidence of loneliness, poor temper, anxiety and falls.

Social care

A stimulating environment includes the provision of social and individual activities. Having opportunities for social interaction, a range of activities, and the choice to be involved or not, are all important. Differences in needs and preferences mean that it is also important to involve tenants in the design of activities.

Assistive technology

Assistive technology, such as movement-activated lighting and bed occupancy sensors, can benefit residents. However, it is essential that residents and staff are given information about what is available and how to use it.

Use of assistive technology packages should be tailored to the individual and be agreed with the resident and their family, including some control over how and when they are active.

Care deliverers should also be alert to the fact that installation costs can deter residents from making use of assistive technology.

Success for families

Information

Involvement of a resident's family in the decision-making about the provision of care is very important. This requires encouragement and support for relatives – dementia is usually an unknown land. Families or friends who wish to minimise risk may unwittingly reduce the independence and empowerment of a person with dementia. Families and friends should be able to discuss their own needs, as well as those of the person living with dementia, and the capacity of the facility to meet them.

Practical Support

The practical and emotional support from the family also plays a highly significant part in helping the resident maintain well-being, identity and independence. The value of staff encouraging and facilitating positive family involvement cannot be overestimated.



Activities

In order that residents' activities are best suited to individual needs, families should be involved in their planning. Families also value good opportunities to relax with residents, for example in cafes and comfortable lounges.

Success for staff

Living with dementia increases the amount of care a resident requires, making substantial demands on members of staff. Dementia care can be stressful, so it is important that staff members are helped to find ways of managing stress.

Having well-trained staff not only improves the quality of life for residents; it also encourages job satisfaction and high staff morale.

Staff members feel effective and fulfilled when they are well-trained, well supervised and empowered. This is enabled by:

- specialist dementia expertise
- clear procedures to address behavioural symptoms
- strong management and leadership
- simple and robust assistive technology that is well explained and integral to service and care planning

Relationships

Person-centred care is best provided when members of staff are encouraged to communicate positively, and at length, with residents. Building relationships with residents helps support them, increase their confidence and reduce their stress. It also increases job satisfaction for staff members themselves.

Training

The distress and behavioural symptoms of some individuals living with dementia can be minimised when staff are well trained to:

- promote tolerance and an ethos of inclusion
- deal with challenging behaviour and difficult situations
- understand a range of topics related to dementia care (e.g. depression, pain, behavioural symptoms, mobility, nutrition and hydration)
- know what characteristics to look for as dementia advances and who to talk to about these
- gauge when treatment for pain may be necessary and when it is successful
- maintain the skills of a person with dementia take positive risks
- understand their responsibilities arising from the Mental Capacity Act 2005

Success for managers

Managers of Housing with Care experience a smooth-running, happy environment when both they and their staff are well supported.

Clear procedures

Clear management and operational procedures aid the running of Housing with Care. In particular, developments have been seen to be successful where there are:

- procedures in place to address behavioural symptoms
- more supervisors are trained to assess and manage behavioural symptoms
- transparent criteria and guidelines for accepting new residents, with an emphasis on the importance of individual assessment and flexibility

Strong support

Successful Housing with Care is best enabled by strong partnership and joint working, and integrated strategies between local social care, health and housing departments. The availability of support from the wider locality (e.g. social services, community nursing and other health services), together with a clear awareness of the cultural and social needs of the community, help build effective extra care environments.



The Consortium and the Review

Living Beyond Dementia is drawn from an extensive review of research undertaken by the Housing and Dementia Research Consortium with funding from the Joseph Rowntree Foundation.

The Consortium was set up in 2008 by four leading UK providers of Housing with Care (Housing 21, Hanover, Anchor and the MHA Care Group) in order to develop robust evidence on dementia care in a Housing with Care setting.

The report is called *Extra Care Housing and People with Dementia**. It provides the evidence for this guide, setting out what has been learned about people with dementia living in Housing and Care by examining all the published and unpublished literature and evaluations produced between 1998 and 2008.

As well as analysing the existing evidence in detail, the report also identified areas where further research is required. The Consortium has subsequently undertaken further work to clarify and prioritise those areas where work has yet to be done. It is planning partnerships within its own membership and with other research

bodies to fill the gaps in the currently available evidence.

Nevertheless, the Consortium's work to date already constitutes an important response to the government strategy in England: *Living Well with Dementia*: a national dementia strategy, published by the Department of Health in February 2009**. As part of its goal of improving dementia services, including the provision of a higher quality of care, that strategy encourages consideration of housing-related services as 'options to prolong independent living and delay reliance on more intensive services'.

Living Beyond Dementia is one step towards providing the information needed to guide policy, encourage good practice, and increase the understanding of residents, families, staff and care providers alike.

* Dutton, R. (2009) *Extra Care Housing and People with Dementia: what do we know about what works regarding the built and social environment, and the provision of care and support? A Scoping Review of the Literature 1998-2008*. Download from <http://www.dhcarenetworks.org.uk/IndependentLivingChoices/Housing/Topics/type/resource/?cid=5844>

** Available at www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_094058. See also Scotland's National Dementia Strategy at www.scotland.gov.uk/Topics/Health/health/mental-health/servicespolicy/Dementia (Accessed October 2010)

The Housing and Dementia Research Consortium was established in 2008 by four leading providers of Housing with Care in the United Kingdom: Housing 21, Hanover, Anchor and the MHA Care Group. With a membership of around 100 individuals and organisations, the consortium's aim is to develop robust evidence on dementia care in a Housing with Care setting.



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