

# Home truths

Housing services and support  
for people with dementia



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**Document purpose** This report provides a broad overview of the key issues relating to housing as experienced by people with dementia. The report summarises existing evidence and presents new evidence from people with dementia and their carers. It makes recommendations to those working in the housing and social care sectors around closer integration, ensuring people with dementia get the information and advice they need and supporting people with dementia to be able to live in the homes of their choice.

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**Target audience** This report is intended for a range of audiences including central and devolved government, policy makers, local government and housing associations. Its recommendations are intended to inform and change practice and policy.

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# Executive summary

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Two-thirds of people with dementia live in the community, mostly in mainstream housing. People with dementia in the community want support to help them maintain their independence and this is widely recognised in government dementia policy. However, there is limited government policy on housing and dementia, beyond identifying the need to monitor and support the development of new forms of housing. There are a range of challenges facing the housing sector and its relationship with health and social care. Housing policy remains distinct from health and social care and many stakeholder organisations involved in housing express concerns about co-ordination between housing, health and social care.

It is widely recognised that much of existing housing is poorly suited to the needs of older people and people with dementia in particular. Where people with dementia have moved into specialist housing they identify benefits and these are documented in the literature. However, while guidance on designing homes and communities for people with dementia does exist, this needs to be more consistently adopted alongside the development of new evidence on design and dementia. Moreover, many people with dementia and their carers want to remain in their existing homes and there are significant barriers to moving, including costs, lack of housing options and a lack of awareness of the housing options that exist.

There are a range of potential sources of information and advice on housing, however little of it is specific to dementia and people with dementia and their carers often face challenges in accessing information about housing choices, options and services. People with dementia and carers who have made adaptations to their homes express strong support for these. However, there remain concerns that, in spite of commitments for increased funding for adaptations, reductions in funding to local authorities may result in restrictions in access to adaptations.

To meet the housing needs of people with dementia, there must be greater commitment to co-ordination of services, provision of information, funding of adaptations and choice in housing options.

## Purpose of report

This report provides a broad overview of the key issues relating to housing as experienced by people with dementia. The report summarises existing evidence and presents new evidence from people with dementia and their carers. It makes recommendations for those working in the housing and social care sectors around closer integration, ensuring people with dementia get the information and advice they need and supporting people with dementia to be able to live in the homes of their choice.

## Methodology

The report is based on a review of current evidence on housing and dementia, including experiences of different forms of housing, adaptations and information, and consideration of government and stakeholder policy.

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In addition, the Society collected new qualitative evidence through focus groups and interviews with people with dementia and their carers. Seventeen people with dementia and carers were involved in two focus groups, four face-to-face interviews and one telephone interview. Focus groups and interviews were carried out in 2011 in England and Northern Ireland.

## Key findings

### Dementia and housing policy

- There are significant difficulties linking housing, health and social care services and support.
- There is only limited emphasis on the needs of people with dementia in current housing policy, but a strong emphasis in dementia policy on supporting people with dementia to remain independent in their own homes.
- Existing government policy on housing and dementia has tended to focus on telehealth and telecare services and on new forms of housing, such as housing with care.
- Much of the UK's current housing stock is poorly designed to meet the needs of older people.
- The importance of information and adaptations is widely recognised.

### Where people with dementia live now

- There are significant barriers to people with dementia moving home, either to specialist housing or within mainstream housing.
- Most people with dementia in the community are likely to be owner-occupiers and there is strong support for home ownership, even for specialist forms of housing. Nevertheless a significant proportion of people with dementia are likely to live in rented accommodation, especially in social housing and housing with care.
- People with dementia and their carers have mixed and often quite strong views on the type of housing they wish to live in and what would be most appropriate to their needs.
- Housing with care can potentially play an important role in supporting people with dementia and fill a gap between mainstream homes and care homes. However, housing with care will not be a suitable or preferred option for all people with dementia.

### Information and adaptations

- Information and advice on housing is crucial to people with dementia making informed choices about housing, but they can struggle to get the information they need.
  - People with dementia often use informal pathways for accessing information on housing and often do not differentiate between different providers of information, or between information on housing and information on social care services.
  - People with dementia and their carers often access adaptations, and satisfaction levels with these are very high.
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- There are a range of sources of funding for adaptations to people's own homes, most prominent of which are disabled facilities grants (DFGs). However, there are concerns that local councils might not allocate money for adaptations while their budgets are under such pressure.

## Principles of design

- Design of housing and the wider environment can play a key role in ensuring people with dementia enjoy a good quality of life.
- The issue of design and dementia is receiving growing prominence, with the publication of design principles, guides and guidelines covering homes, care environments and the wider environment.
- Challenges remain in the adoption and uptake of design principles and guidelines, as well as ongoing research challenges to understand what forms of design work best.

## Recommendations

### 1 Local authorities, homebuilders and governments should recognise that appropriate housing services and support are key mechanisms for effective support of people with dementia in the community.

- Alzheimer's Society reiterates the recommendation from the Support. Stay. Save. report (Alzheimer's Society, 2011) that people with dementia need to have access to care and support to enable them to live independently in their own homes and services must be prioritised to achieve this.
- Housing should be included within Joint Strategic Needs Assessments in England and health and social care planning in Wales and Northern Ireland.
- Local authorities should work with health organisations in redirecting spending from acute and long-term sectors into provision of support in people's own homes, including handyperson, information, advice and adaptation services.
- The housing sector should fully engage with the development of dementia friendly communities.

### 2 There should be a choice of housing options and tenures available to people with dementia, including mainstream and specialist housing.

- Local authorities should work with housing developers and housing associations to ensure a mixed economy of housing options.
  - Housing should be available on a range of tenures, including owner-occupied specialist housing.
  - More research should be commissioned into housing and dementia, including housing with care. Research should consider the pros and cons of models of housing, including investigating the limits of housing with care as an alternative for people with dementia.
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### **3 People with dementia, their families and carers, should have access to information and advice on housing options, handyperson services and sources of funding for adaptations and alterations.**

- People with dementia and their families should be provided with information and advice on housing and housing options from the point of diagnosis.
- Staff working in housing should be trained in understanding dementia and supported to provide information on local services and housing options.
- Local commissioners should ensure first contact services are able to provide advice and information on housing and housing services, alongside information on social care and third sector services.
- Local authorities should ensure all funding for disabled facilities grants (DFGs) is allocated for this purpose and ensure they utilise discretionary powers to provide adaptations, information and low level support services.

### **4 People with dementia should have access to homes designed with their needs in mind.**

- Homebuilders should consider existing design principles when developing new housing, especially housing aimed at older people.
  - All new housing should be built to the Lifetime Homes standard.
  - Further research should be carried out into the preferences and needs of people with dementia in terms of housing and wider environmental design.
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# 1 Introduction

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Two-thirds of people with dementia in the UK live in their own homes in the community, making the provision of appropriate housing and housing support services essential to meeting the needs of the 800,000 people living with dementia in the UK (Alzheimer's Society, 2012a). There has been considerable expansion in the development of new forms of housing in recent years, and these are often considered as alternatives to residential care homes (ILC-UK, 2011).

However, these forms of housing only make up a small proportion of housing stock, resulting in a lack of accommodation options between mainstream general housing and long-term care in a care home. While in many instances care homes may be the appropriate settings for care of people with dementia, people with dementia are too often admitted early into long-term care because of a lack of support and care in the community (Alzheimer's Society, 2011). Irrespective of place of residence, people with dementia and their families may need access to information and adaptations to enable them to maintain their independence.

Previous work carried out by Alzheimer's Society has identified that remaining in their own homes is of crucial importance to people with dementia and their carers (Alzheimer's Society, 2011). There is now considerable and growing evidence that people with dementia, even advanced dementia, can express opinions about their quality of life (Alzheimer's Society, 2010a) and want services and support to do more than only meet care needs (Alzheimer's Society, 2011). There is a recognised need that a whole community response is needed to meet the challenge of dementia (DH, 2012).

Research to inform the Dementia Action Alliance's National Dementia Declaration identified that people with dementia expressed aspirations around quality of life and remaining part of the community (DAA, 2010). These aims correlate closely with the aims of national strategies for dementia, social care and health care, which strongly focus on tailoring services and supporting people in their own homes for as long as possible. Housing and housing services can play an essential role in supporting people with dementia to achieve aspirations around quality of life, independence and remaining part of their community.

The aim of this report is to summarise the current situation of policy and strategy relating to housing and dementia. The report is intended for housing bodies, local and national government and policy makers and researchers in the housing sector. It will outline the key issues of housing relevant to dementia and present evidence about people with dementia and carers' experiences and aspirations for housing and housing services.

The report covers the following areas:

- Dementia and housing policy
  - Where people with dementia live now
  - Information and adaptations
  - Principles of design.
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The report makes recommendations for housing bodies and for local and national government on how to ensure housing and housing services can meet the needs and aspirations of people with dementia. It presents several case studies, which show how some housing services are working to meet the needs of people with dementia.

### 1.1 Methodology

This report is informed by qualitative research carried out among people with dementia, carers and those working in the housing sector. The methodology followed to inform the report was a review of existing policy and strategy relating to housing and dementia and a series of focus groups and interviews with people with dementia and carers. In total 17 people with dementia and carers were involved in research. These interviews and focus groups have been described as Experiences of housing (EoH) research in the report.

- In total five interviews were conducted, four with carers and one with a person with dementia.
- Two focus groups were conducted, one with four carers and one with one carer and six people with dementia or suspected memory problems.
- Interviews were conducted with people living in mainstream housing as well as those in specialist housing. One carer who participated cared for someone who now lived in a care home.
- EoH focus groups and interviews were carried out in England and Northern Ireland and included people in mainstream and specialist housing. Participants in EoH were recruited with the help of colleagues from Alzheimer's Society services and the ExtraCare Charitable Trust.

The Society also sought views from colleagues in leading national organisations working in the housing sector to inform the direction of research. The report was peer reviewed by Sue Garwood, independent extra care specialist, Dr Julie Barrett, Research Coordinator, Housing and Dementia Research Consortium and Jeremy Porteus, Director, Housing Learning Improvement Network (LIN).

### 1.2 Context of dementia

The term dementia describes a set of symptoms that includes loss of memory, mood changes and problems with communication and reasoning. These symptoms occur when the brain is damaged by certain diseases, including Alzheimer's disease and damage caused by a series of small strokes. Dementia is progressive, which means people with dementia and their carers are coping with changing abilities over time. These include the person's capacity to make decisions about major life changes, as well as day-to-day matters. Eventually they will need help with all their daily activities, which may be provided by family carers or numerous agencies spanning health and social care and others.

There are 800,000 people with dementia in the UK, a figure set to rise to 1 million by 2021. Most care of people with dementia is provided by the 670,000 family carers of people with dementia (Alzheimer's Society, 2012a). However, providing care to people with dementia is core business of health and social care services. Two-thirds of residents in care homes have a

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form of dementia (Alzheimer's Society, 2007), up to a quarter of hospital beds are occupied by someone with dementia (Alzheimer's Society, 2009a) and home care workers regularly provide care to people with dementia (Alzheimer's Society, 2011).

Health and social care services often struggle to provide good quality care to people with dementia. In 2007, the National Audit Office in England found health and social care spending on dementia was often in the later stages of dementia and often did not lead to good outcomes for service users (NAO, 2007). Similar challenges were identified by the Bamford review of dementia services in Northern Ireland (Bamford Review, 2007).

People with dementia and their carers often struggle to gain access to support. Only 43% of people with dementia have a formal diagnosis of dementia (Alzheimer's Society, 2012b), which may impair access to services for those undiagnosed (Alzheimer's Society, 2011). Furthermore, the current system of funding social care means many people with dementia cannot access support until their needs meet crisis level, inhibiting provision of support in the community (Alzheimer's Society, 2008a).

Alzheimer's Society's Dementia tax report found many people with dementia and carers were paying substantial amounts for care and few felt their needs were being met by social services support (Alzheimer's Society, 2008a). Subsequent surveys carried out by the Society have reaffirmed the high costs many people with dementia and their carers pay for care (Alzheimer's Society, 2009b; 2010b). Alzheimer's Society's 2008 Home from Home report found many care homes were not providing good quality dementia care. Issues raised included a lack of opportunities for social interaction and a lack of activities (Alzheimer's Society, 2008b).

In hospitals, the Society's Counting the Cost report found unacceptable variation in the care of people with dementia on hospital wards, with people with dementia staying in hospital for longer than other people admitted for the same reason and one third of people admitted from their own home being discharged into a care home (Alzheimer's Society, 2009a). Subsequent reports by the Care Quality Commission (CQC) and the Royal College of Psychiatry support Counting the Cost's conclusion that there is unacceptable variation in the quality of care provided to people with dementia on hospital wards (CQC, 2011; RC Psych, 2011).

In response to the challenge of dementia, governments in England, Wales and Northern Ireland have published strategies and plans for improving dementia services (DH, 2009; Welsh Assembly Government, 2010a; 2011; DHSSPS, 2011a). All strategies strongly emphasise supporting people with dementia to remain independent in their own homes and all make a limited reference to the role of housing and associated services in achieving this.

There is also now growing consensus around the importance of community in supporting people with dementia and maintaining their quality of life. The Society's Dementia 2012 report found many people with dementia are excluded from community and society, with many reporting losing friends and experiencing loneliness, anxiety and depression. The report called for the creation of communities which are dementia friendly (Alzheimer's Society, 2012c).

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In March 2012, the Prime Minister launched the Prime Minister's challenge on dementia. This challenge set out clear commitments to make the UK a world leader in dementia care and research and acknowledged that the government and society's response to dementia has not been adequate. The challenge is formed of three key elements: driving improvements in health and social care, creating dementia friendly communities and improving dementia research (DH, 2012).

### 1.3 Context of care and support of people with dementia in their own homes

Two-thirds of people with dementia (over 500,000) in the UK live in their own homes in the community (Alzheimer's Society, 2012a). The majority of people with dementia in the community live in mainstream forms of housing which are not specialised towards the needs of older people. Around a third of these people live alone, either with the support of a carer who lives elsewhere, or without the support of an identified carer (Miranda-Castillo et al, 2010).

Evidence strongly suggests people with dementia and their carers want to be supported in their own homes in the community. Alzheimer's Society's Support. Stay. Save report found people with dementia and their carers wanted to be supported in their own homes in the community. Support. Stay. Save. also found that independence and being part of the community were identified as important by people with dementia and their carers (Alzheimer's Society, 2011). This finding is supported by other research to inform the development of the Dementia Action Alliance's National Dementia Declaration (DAA, 2010).

The importance of independence and control over life was also identified in the Society's My name is not dementia report, which found people with dementia, including advanced dementia, are able to express opinions about quality of life and what is important to them (Alzheimer's Society, 2010a). The Society's Dementia 2012 report identified the importance of community to people with dementia (Alzheimer's Society, 2012c).

Improving support in the community, as well as increasing communities' abilities to support people with dementia, are therefore essential components of meeting the aspirations of people with dementia to remain at home, remain active, be independent and enjoy a good quality of life. Communities themselves have a responsibility to achieve this and housing and housing services are essential to ensuring this. There is significant potential for the housing sector to play a key role in developing and supporting dementia friendly communities.

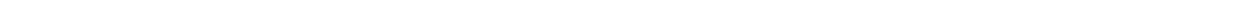
Supporting people to remain in their own homes in the community is a key priority of the National Dementia Strategy for England (NDSE) and broader health and social care policy (DH, 2009). However the Support. Stay. Save. report found half of people with dementia were not getting enough support in their own homes and that there had been little evidence of service expansion since the Society conducted its Dementia tax survey in 2008 (Alzheimer's Society, 2011).

Support. Stay. Save. identified high levels of satisfaction with the services respondents had received while the person with dementia was living in their own home. However, a significant minority of respondents were dissatisfied with individual services. Other reports have also identified significant challenges in the care and support of people with dementia in their own homes. An inquiry by the Equality and Human Rights Commission (EHRC) found home care

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often led to violations of human rights, which the EHRC identified were frequently as a result of poor commissioning practices (EHRC, 2011). The Society's Dementia 2012 report found people with dementia were often at risk of exclusion and isolation and communities needed to do more to support them (Alzheimer's Society, 2012c).

Too often, lack of availability of support in the community has meant people with dementia are admitted to long-term and acute care earlier than expected because of insufficient support in the community (Alzheimer's Society, 2011). In addition, there is a lack of opportunity for people to access forms of accommodation between mainstream homes in the community and long-term care in a care in care homes.



## 2 Dementia and housing policy

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### Summary

- There are significant difficulties linking housing, health and social care services and support.
- There is only limited emphasis on the needs of people with dementia in current housing policy, but a strong emphasis in dementia policy on supporting people with dementia to remain independent in their own homes.
- Existing government policy on housing and dementia has tended to focus on telehealth and telecare services and on new forms of housing, such as housing with care.
- Much of the UK's current housing stock is poorly designed to meet the needs of older people.
- The importance of information and adaptations is widely recognised.

### 2.1 Introduction

The direction of health, social care and housing strategy across England, Wales and Northern Ireland is around supporting people in their own homes (DCLG, 2011; DH, 2009; DH, 2010; Welsh Assembly Government, 2007; DHSSPS, 2011b). Specific to older people and dementia, strategy emphasises the development of new forms of housing to meet people's needs (DCLG, 2008, DH, 2009; Welsh Assembly Government, 2011; DHSSPS, 2011a). In addition, several recent stakeholder and research reports have underlined the need for provision of new forms of housing and outlined challenges faced by older people around information, ensuring adaptations are made to their homes and promoting joined up working with health and social care (eg APPG HCOP, 2011).

This section covers key aspects of housing policy in England, Wales and Northern Ireland relevant to people with dementia. It also looks at recent evidence published by key stakeholders on housing.

### 2.2 National policy and strategy

Direction in housing strategies varies across England, Wales and Northern Ireland. Currently, the Northern Ireland Executive and the Welsh Government are more directly involved in housing policy (Welsh Assembly Government, 2010b), while the coalition government in England has emphasised greater local autonomy over housing and planning for local government (DCLG, 2011).

#### 2.2.1 England

The coalition government's 2011 housing strategy, *Laying the Foundations*, strongly emphasises the role of the housing market as an engine for economic growth. Specifically to older people, the strategy recognises the importance of information and adaptations,

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highlighting government commitments for investment in the FirstStop advice service, disabled facilities grants and handyperson services. The government's strategy also highlights their wish to support the development of equity release products to fund adaptations and encourage local authorities to build a range of housing types to meet the needs and aspirations of older citizens (DCLG, 2011).

While Laying the Foundations prioritises certain areas, such as increasing funding allocated to disabled facilities grants to £185 million by 2013/14 (DCLG, 2011) actual decisions on spending these monies will largely be left to local authorities, who have seen substantial overall reductions in their central government capital and revenue grant funding streams (HM Treasury, 2010).

Laying the Foundations also draws together policy and legislative changes which were announced before publication of the strategy around increasing numbers of homes built, supporting greater flexibility in social housing rents and supporting sustainable high quality home building. It also strongly emphasises localism, with removal of central targets and greater local autonomy for local authorities in terms of housing (DCLG, 2011). Criticism has been levelled that these changes risk undermining emphasis on the need to build more homes and may lead to those in social housing having less stable tenancies (National Federation of Tenant Management Organisations, 2011).

In addition, it is also worth noting that the previous government set out a strategy specific to housing and older people. Lifetime homes, lifetime neighbourhoods, which was published in 2008, highlighted key priorities which largely remain in place under the new coalition arrangements, including:

- creating national housing advice and information services and strengthening local housing information services (FirstStop)
- increasing funding for disabled facilities grants, which provide funding for adaptations to people's homes
- stating that all new housing should be built to a set of 'lifetime homes' standards and incentivising good design locally
- seeking greater co-ordination of assessment, service provision and commissioning across housing, health and social care.

Lifetime homes, lifetime neighbourhoods made limited statements around dementia, although it acknowledged the need for models of housing and housing support teams to meet the needs of growing numbers of people living with dementia in England (DCLG, 2008).

The National Dementia Strategy for England also makes some recommendations specific to housing. The NDSE strongly advocates supporting people with dementia to remain at home in the community and providing services that enable this, including information and advice. It calls for monitoring of the development of new housing models, including extra care housing. It also calls for monitoring of the development of assistive technology and telecare and more research into these. It also states that housing services and staff must be trained and supported to provide best quality care and support to people with dementia (DH, 2009).

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The Prime Minister's challenge on dementia, while not explicitly referencing housing, highlights the need for supporting the development of dementia friendly communities. The challenge commits to action to improve awareness and understanding of dementia, and to bring communities together to tackle stigma, reduce isolation and ensure people with dementia can remain active and independent (DH, 2012).

### 2.2.2 Wales

In Wales, the latest strategy on housing was published in April 2010. *Improving lives and communities: Homes in Wales* outlines the approach to housing being taken by the then One Wales Government:

- Provide more housing of the right type and offer more choice.
- Improve homes and communities, including the energy efficiency of new and existing homes.
- Improve housing-related services and support, particularly for vulnerable people and people from minority groups (Welsh Assembly Government, 2010b).

*Homes in Wales* recognises the challenge of the ageing population and states that this has significant implications for the design of houses. The strategy states support must be available to help people live independently for as long as possible. It makes limited recommendations on dementia focusing on the role of extra care housing schemes in supporting people with dementia (Welsh Assembly Government, 2010b).

Housing is identified as an issue in the dementia vision and action plans of the Welsh Government. Both the action plans and the Welsh Government Dementia Vision highlight the importance of supporting people in the community and the need for provision of information and advice. The vision states people with dementia wish to 'remain within their communities for as long as possible and in the homes of their choice' (Welsh Assembly Government, 2011; 2010a).

The key priorities recognised around housing in the action plans include expanding extra care housing, training for housing association staff and the development of evidence on the benefits of assisted technology, including telecare (Welsh Assembly Government, 2011; 2010a).

### 2.2.3 Northern Ireland

The Northern Ireland Housing Executive (NIHE), which oversees housing policy implementation in Northern Ireland, has recognised the importance of meeting the housing needs of older people in Northern Ireland. A 2010 report to the executive identified that a significant proportion of the expected growth in housing would be in housing occupied by older people. The report identified that older people wanted to retain their independence in their homes for as long as possible and acknowledged that in many cases people would require some support (Paris, 2010).

The NIHE produced a strategy for older people for 2008–2010. This strategy identified 15 objectives, including better use of adaptations and improved advice and information, and developing housing options for people with dementia. The NIHE Older People Policy also

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recognised the need for developing housing for older people with dementia, including research to underpin such models (NIHE, 2008).

This had previously been acknowledged in the 2007 Bamford review, which led to the draft strategy. The review recommended that most people with dementia would want to remain in their own homes, but suggested there was a need for a choice of supported self-contained dwellings (Bamford, 2007).

In the Northern Ireland regional dementia strategy, the roles of specialised housing, adaptations to people's own homes and assisted technology are also emphasised. The strategy identifies the need for close working between the Department for Health and Social Services and the Northern Ireland Housing Executive around new forms of housing (DHSSPS, 2011a).

#### 2.2.4 Stakeholder evidence on housing

Recent years have seen several other influential reports looking at how the housing system meets the needs of older people. While these reports do differ in recommendations and focus, there is considerable consensus on several key issues. These include that existing housing is not geared towards the needs of older people and that there need to be closer links between health, social care and housing services (APPG HCOP, 2011; Ball, 2011; LGG, 2010, Shelter; 2012).

The 2009 report of the Housing our Ageing Population: Panel for Innovation (HAPPI) group looked at international evidence and examples of housing schemes designed to meet the needs of older people (HAPPI, 2009). Building on the work of Lifetime homes, lifetime neighbourhoods, the HAPPI report outlined the following key themes for meeting the housing needs of older people. Key recommendations of the HAPPI report included:

- The time has come for a national effort to build the homes that will meet our needs and aspirations as we all grow older.
- We should all plan ahead positively, creating demand for better choice through a greater range of housing opportunities.
- Housing for older people should become an exemplar for mainstream housing, and meet higher design standards for space and quality.
- Local planning authorities should play a key role to ensure delivery of desirable housing in great places, tuned to local need and demand.

The HAPPI report also highlighted that there was a scarcity of properties ready for later life and that, as a result, many people went into residential care earlier than they needed to. The report outlined numerous examples of best practice in meeting the housing needs of the ageing population.

Shelter's 2012 report, *A better fit*, also highlights the lack of specialist housing for older people. Polling evidence used in *A better fit* highlights that many older people want to remain in their current home for as long as possible. The report states decisions for older people to move are often made later in life or at a time of crisis (Shelter, 2012).

In your lifetime, the National Housing Federation's 2010 report on housing for older people, outlined a series of recommendations. These include prioritisation of housing and support in

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housing strategies, the need for consistency in assessment and delivery of aids and adaptations, and the need for 24 hour care and support models to continue in the era of personal budgets (NHF, 2010).

Specific to dementia, In your lifetime makes the following recommendations:

- Local authority commissioners should ensure that there is a portfolio of service provision available which has an overall emphasis on personalisation and choice.
- Local authorities should recognise the role for commissioned services to operate in conjunction with individual budgets.
- Department of Health Commissioning guidance on the implementation of personalisation should recognise the circumstances and key contribution of sheltered and extra care housing (NHF, 2010).

The LGG, in their report *Good homes in which to grow old?*, suggests there is a need for devolution of planning to the local level. The report called for regional planning resources to be invested in increasing local planning capacity and states councils are best suited to assess and direct resources to meeting the challenge of an ageing society (LGG, 2010). The recent consultation on the National Planning Policy Framework and its proposition supports this approach. At the time of writing, a sector-led toolkit is being written to provide local councils with guidance and practice examples on planning for older people's housing to assist them make strategic decisions that may reflect the local demand for such accommodation.

In 2011, the NHF's report, *Breaking the mould* asserted that the shift towards localism and an ageing population presents an opportunity for significant innovation in meeting the housing needs of older people. The report, partly based on focus groups and polling carried out with older people, outlines nine key themes that older people reported they wanted from their housing:

- accessible
- spacious and attractive
- safe and secure
- in an age-friendly environment
- offers freedom, choice and flexibility
- has help at hand
- provides flexible, personalised support
- lets you socialise and feel included
- allows you to make decisions.

*Breaking the mould* provides numerous examples of innovation within the housing sector around a range of issues, including equity release, provision of low level community services, specialist services for people with dementia and extending home ownership. It calls on local government and housing providers to proactively pursue innovative solutions to meeting the needs of older people (NHF, 2011).

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The All Party Parliamentary Group on Housing and Care for Older People (APPG HCOP) published the findings of its inquiry into Living Well at Home, which heard evidence from stakeholders across the housing and care sectors (APPG HCOP, 2011).

The APPG HCOP concluded that lack of joined up working, delays in social care and adaptation assessments, as well as inappropriate forms of housing were all contributing to many older people being unable to remain independent in the community and going into long-term care earlier than expected. Specific to close working between housing, health and social care, the APPG HCOP highlighted that an absence of any payment by results means there is little or no incentive for joint working between housing and health and social care, and called for Joint Strategic Needs Assessments to fulfil this. The report makes recommendations for improved information services, better access to funds for adaptations and closer working between health, social care and housing (APPG HCOP, 2011).

## 2.3 Conclusions

National housing policy for older people in England, Wales and Northern Ireland focuses on the funding of adaptations, information services and supporting good design. Where housing and dementia policy exists, it identifies the importance of supporting people in the community – looking at the role of new forms of housing with care, alongside the potential for telecare and telehealth in supporting people with dementia in their own homes. Housing strategies also identify the need for providing training on dementia for those working in the housing sector.

While these areas are also considered by stakeholders, the evidence outlined above suggests there is concern over the lack of integration between housing and health and social care services and an inadequate response to meet a growing market of older consumer/service user. For housing to be able to meet the needs and lifestyle choices of people with dementia and their carers, it has to be considered in conjunction with other areas of public policy.

### Recommendation 1

Local authorities, homebuilders and governments should recognise that appropriate housing services and support are key mechanisms for effective support of people with dementia in the community.

- Alzheimer's Society reiterates the recommendation from the Support. Stay. Save. report (Alzheimer's Society, 2011) that people with dementia need to have access to care and support to enable them to live independently in their own homes and services must be prioritised to achieve this.
  - Housing should be included within Joint Strategic Needs Assessments in England and health and social care planning in Wales and Northern Ireland.
  - Local authorities should work with health organisations in redirecting spending from acute and long-term sectors into provision of support in people's own homes, including handyperson, information, advice and adaptation services.
  - The housing sector should fully engage with the development of dementia friendly communities.
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# 3 Where people with dementia live now

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## Summary

- There are significant barriers to people with dementia moving home, either to specialist housing or within mainstream housing.
- Most people with dementia in the community are likely to be owner-occupiers and there is strong support for home ownership, even for specialist forms of housing. Nevertheless a significant proportion of people with dementia are likely to live in rented accommodation, especially in social housing and housing with care.
- People with dementia and their carers have mixed and often quite strong views on the type of housing they wish to live in and what would be most appropriate to their needs.
- Housing with care can potentially play an important role in supporting people with dementia and fill a gap between mainstream homes and care homes. However, housing with care will not be a suitable or preferred option for all people with dementia.

## 3.1 Introduction

The types of housing people with dementia live in and whether they own or rent their housing can impact on their support needs as well as on their access to services and support. This section looks at people with dementia moving to new forms of housing and the forms of housing and tenancy that exist.

## 3.2 Barriers and opportunities for moving

For a person with dementia, moving from one environment to another has the potential to be confusing and disorientating. People with dementia may be familiar with their home environment and may have co-morbidities such as sight loss that make navigating a new environment even more challenging. However, more appropriate environments also have the potential to reduce the risk of falls and other accidents and potentially allow people to retain independence as opposed to moving into long-term residential care.

Generally, older people are much less likely to move than younger people. In England, only 3% of 65–74 year olds and 2% of 75 year olds moved in 2008. This compares to in excess of 50% of 16–24 year olds moving in the same year (Ball, 2011).

There is mixed evidence on the impact that moving from one environment to another has on people with dementia. Some studies on people with dementia in care homes suggest there is not conclusive evidence that moving from one care home to another has a significant impact on life expectancy (Nirenberg, 1983; Mirotnik and Los Kamp, 2000).

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However, some studies in care homes have suggested moving has a negative impact on behavioural symptoms of dementia (Macdonald et al, 2004) and there is significant anecdotal evidence that changing environments can be confusing for people with dementia, especially those in the moderate to later stages.

Decisions to move may be based around the impact of dementia or other care needs. For example, people may decide to move to specialist housing, smaller or more manageable properties or to housing nearer family or friends. Decisions to move may also be influenced by availability of housing options and choices, or may be unrelated to dementia or support needs.

The decision to move to a new home is often a daunting one, since many older people have attachment to their current home. In addition, there may be significant costs associated with moving, including mortgage fees, stamp and removal, and utility costs (Shelter, 2012). For people with dementia who may be on low pension incomes, have much of their wealth made up in housing equity or savings, and face existing care costs, these costs are potentially prohibitive.

Furthermore, the well recognised lack of availability of homes designed around the needs of older people is also likely to act as a significant barrier to people moving (Shelter, 2012). This is particularly likely to be the case for people with dementia who have specialist needs.

Among those EoH participants who said the person with dementia had moved, whether to mainstream or specialist housing, the catalysts for decisions to move were often around concerns with safety and challenges in the home, particularly with stairs. Moves were generally considered positive, although there were also expressions of regret from some participants.

**‘We were living in a house that wasn’t suitable for my wife’s medical needs. We had stairs and she can’t walk up the stairs. She suffers from bad legs. The stairs were really murdering and that’s why we got the bungalow.’**

**Carer of person with dementia in rented mainstream housing**

**‘It was hard to get things done and the stairs: I was scared at night of her getting up. You miss having your own home obviously.’**

**Carer of person with dementia in rented specialist housing**

**‘It was her safety. We knew she wasn’t able to live on her own anymore.’**

**Carer of person with dementia in rented specialist housing**

In several cases the needs of the carer were the catalyst for the move, rather than the needs of the person with dementia.

**‘We lived in a flat before. I loved that place. If I had help I would have stayed, but I couldn’t cope with the stairs.’**

**Carer of person with dementia in owner occupied mainstream housing**

**‘I’ve got Parkinson’s and my wife has Alzheimer’s. The reason we came here was me getting Parkinson’s, not my wife getting Alzheimer’s.’**

**Carer of person with dementia in owner occupied specialist housing**

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Most EoH participants reported concerns about the person with dementia going into a care home until it was necessary and were keen to delay entry to care for as long as possible. Indeed, evidence suggests that the advantage of housing with care options such as extra care housing is that couples can stay together in the knowledge that there is assistance on hand to provide personal care and/or support, as well as providing some respite for the principle carer in the relationship (ILC-UK, 2011).

**‘My husband’s so scared for getting put into a home.’**

**Carer of person with dementia in rented mainstream housing**

**‘I wouldn’t want to put her into a care home. I want to stay with her for as long as possible. To part with her; I couldn’t do that. Unless it came to something serious and I couldn’t look after her.’**

**Carer of person with dementia in rented mainstream housing**

However one participant whose mother had just gone into residential care highlighted they felt it was the appropriate move.

**‘At this point I would have to lift her...and I just couldn’t cope with the behaviour.’**

**Carer of person with dementia**

In his report on owner-occupied retirement housing, Ball argues that the low numbers of moves are a result of a mixture of a lack of availability of housing to buy, and a general preference for older people remaining in their own home. He proposes a series of recommendations aimed at increasing the amount of owner-occupied retirement housing available (Ball, 2011).

The APPG HCOP also states that a lack of availability of suitable housing, high costs of moving and a lack of information act as barriers to older people accessing appropriate housing. The APPG HCOP highlighted that, while people over 65 own an estimated 80% of private wealth in the UK, there was a lack of viable equity release products to enable people to access this funding (APPG HCOP, 2011), an issue also picked up in the NHF’s report *Breaking the mould* (NHF, 2011). Shelter have also identified a lack of available options for older people, as well as a lack of awareness of the housing options that do exist (Shelter, 2012).

Similar findings were also outlined in two articles for the Housing Learning Improvement Network on downsizing to mainstream and specialist housing (Sutherland, 2010; 2011). In these articles, Sutherland outlined advantages for both individuals and wider society of older people downsizing, including health and quality of life benefits. However, she highlighted that there were a range of challenges inhibiting people from moving, including lack of options and significant costs associated with care (Sutherland, 2011). These challenges are likely to be more acute for people with dementia, who have specialist needs and often face very significant care costs.

### **3.3 Ownership and occupation of housing**

In the UK, the majority of people own their own home; either through a mortgage or outright. The proportion of people who own their own home varies across the UK and between specialist and mainstream housing. Generally those over the age of 65 are more likely to own their own home and the same is likely true of people with dementia.

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### 3.3.1 Home ownership

People with dementia are more likely than not to be owner-occupiers. Levels of ownership are high among older households in the UK, with 75 % of over-65 households in England owner-occupied (Ball, 2011). While there has been a recent decline in home ownership rates (DCLG, 2012), home ownership among those aged 65 and over has risen steeply in recent decades. In England, between 1981 and 2008/9, home ownership rates rose from 50 % to 79 % among 65–74 year olds and from 47 % to 73 % among those over 75 (DCLG, 2012). Retired people make up 57 % of owner-occupied households (Ball, 2011). It is therefore essential that the housing market for owner-occupiers is suited to support people with care needs.

While most people with dementia are over the age of 65, there are at least 17,000 people with early onset dementia in the UK (Alzheimer's Society, 2012a). Many people with early onset dementia will face outstanding mortgage costs and experience significant financial challenges following the development of dementia.

Several EoH participants strongly identified the importance of owning a home, or expressed regret if they had been forced to sell their home to move into more appropriate housing.

**‘Typical suburban semi, lived in since the 1970s. Yes, we own it; mortgage paid off!’**

**Carer of person with dementia in owner occupied mainstream housing**

**‘If I had the money I would have bought because we did own our own home and it was fantastic when they were all growing up and they were all with us. But then the money went down. In an ideal world I would love to buy our own home.’**

**Carer of person with dementia in rented mainstream housing**

**‘We owned a house. You’ve had your own home for so long. I would buy if the option was there, but it isn’t.’**

**Carer of person with dementia in rented specialist housing**

Owning a home allows people with dementia and their carers greater control over decisions to have adaptations made to their home and provides capital for moving to another property, should the person with dementia and their carer decide this is appropriate. However, low pension incomes and high costs of moving or funding adaptations can mean people with dementia who own their own homes may face barriers in either adapting their home or moving to other forms of housing they feel may be better suited to their needs. Similarly, people with dementia often need to downsize in order to release funds from their homes to pay for care and support.

### 3.3.2 Tenancy

In England, around a quarter of householders over 65 years of age live in rented accommodation. The majority (80 %) of renting householders over 65 rent from a social landlord. The remaining 20 % rent from a private sector landlord (Ball, 2011). This contrasts starkly with the population as a whole, where private renting is much more common. Households over the age of 65 therefore represent a very significant proportion of social housing tenants and only a small minority of private sector tenants. However, there is likely to

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be significant variation across the UK and there are some areas of the country where a significant proportion of households over 65 rent from the private sector.

In the UK there remains a longstanding lack of availability of social housing. This is especially an issue in London and the South East, where high property prices have led to high market rental rates. This means many are unable to afford to buy property or rent from the private sector, putting pressure on social housing. Furthermore there is also very little specialist or purpose-built private rented accommodation for older people (Miller, 2010), an issue which is likely especially acute for people with dementia who may have specialist needs in terms of housing.

People with dementia in social housing and private rented housing may have limited assets and as such may be more likely than owner-occupiers to meet eligibility for state funded social services for care and support. People in rented accommodation are also unlikely to be able to decide to fund adaptations to their own homes. However, people in rented accommodation, especially social housing, may have greater flexibility in terms of moving to new properties because of not having to rely on selling their current property.

### 3.4 Forms of housing

For the purposes of this report, the Society is categorising housing according to the groups set out in the 2009 HAPPI report: mainstream housing and specialised housing (HAPPI, 2009). EoH research included participants from both mainstream and specialist housing.

#### 3.4.1 Mainstream housing

Mainstream housing is unlikely to have been designed for people with special needs and has no integral support services. The majority of older people in the UK live in such housing, with 89 % of older people in England living in mainstream housing (Harding, 2008). There is a widespread acceptance that much mainstream housing is poorly designed for the support needs of older people. The APPG on Housing and care for older people inquiry, Living well at home, found that the current housing supply was unable to adequately meet the needs of an ageing population and that unsuitable housing is often a reason for older people being admitted to residential care or hospital (APPG HCOP, 2011).

The LGG's Good homes to grow old (LGG, 2010) and Lifetime homes, lifetime neighbourhoods (DCLG, 2008) also recognised that housing was poorly designed to meet the needs of an ageing population. The latter identified a need to build to standards better suited to people's needs. This is likely to particularly impact people with dementia, who may especially struggle in poorly designed mainstream housing. DCLG is currently working with industry on streamlining all standards relating to construction (DCLG, 2008).

Not all mainstream housing is poorly adapted to the needs of older people or people with dementia. Within the last decade, newly built housing may conform to more inclusive and accessible standards such as the Lifetime Homes standards. In other instances, people may have made alterations to housing or fitted adaptations to make it better suited to their needs.

Some EoH participants who lived in mainstream housing expressed concerns about having trouble coping with the property and outlined challenges that they faced.

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**‘The house is too big. There’s three bedrooms and the two rooms downstairs. I don’t need all that space. It’s harder to clean.’**

**Carer of person with dementia in owner-occupied mainstream housing**

**‘We’re up on the top of a hill. When the kids left and they all got married; it’s not suitable for me and my wife at the moment. It’s too far on the top of the hill.’**

**Carer of person with dementia in rented mainstream housing**

However, other EoH participants expressed a strong desire to remain in their current mainstream homes:

**‘No way we’d sell the house and buy a bungalow. Why should I have all that upheaval; it’s too complicated. We’ll be taken out the house in a box!’**

**Carer of person with dementia in owner-occupied mainstream housing**

**‘We’ve been in the same house for 52 years. We just love to get home, that’s our comfort zone.’**

**Carer of person with dementia in owner-occupied mainstream housing**

### 3.4.2 Specialist housing

Specialist housing is housing designed specifically for older people or people with care needs. Typically, for people to move into specialist housing they must have some form of care or support need. The Elderly Accommodation Council estimated the number of specialist housing units in 2010 to be around 533,000 (Shelter, 2012). The HAPPI report in 2009 stated that specialist properties for older people in England represented only around 9% of all 65+ households (HAPPI, 2009).

Most specialist housing is available to rent, primarily from the social housing sector, with only limited numbers of properties available on an owner-occupation basis (Shelter, 2012). Several researchers and reports have highlighted this as a factor impeding the development and uptake of specialist housing and explaining the tendency for people with dementia to go straight from mainstream housing to long term care (Ball, 2011; APPG HCOP, 2011; Sutherland, 2011; Shelter, 2012).

There are typically a range of types of specialist housing; the HAPPI report identifies five types of housing as:

- sheltered or retirement housing
  - very sheltered or assisted living housing
  - extra care housing
  - close care housing
  - retirement villages (HAPPI, 2009).
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This report considers sheltered housing on its own but has combined the other types of housing under the term ‘housing with care’, since these forms of housing all include on-site services and support that are not available in sheltered housing.

### 3.4.2.1 Sheltered housing

The HAPPI report estimated that 85% of specialist housing for older people in England was in the form of sheltered housing (HAPPI, 2009). However, in areas where there has been significant building of other forms of specialist housing, sheltered housing may be less dominant.

The proportion of residents in sheltered housing schemes living with dementia is unknown (Torrington, 2006), but potentially could be very high. Much of the current stock of sheltered housing was built in between the 1940s and 1970s and many occupants have lived in schemes for extended periods of time. Some providers of sheltered housing provide training to staff on dementia and the need to train staff in sheltered housing has been recognised as a need in dementia and housing strategies in England, Wales and Northern Ireland (DH, 2009; Welsh Assembly Government, 2010a; DHSPSS, 2011a). However, there remain no requirements for staff to have training on dementia.

There is dispute regarding the role that sheltered housing schemes can play in supporting people with dementia. A review published in 1995 outlined that sheltered housing could potentially play an important role supporting people with dementia if sufficient opportunities for social interaction were available (Kitwood et al, 1995). However, recent years have seen evidence that challenges this belief, with questions raised around the appropriateness of sheltered housing.

Some researchers have argued the lack of provision of on-site care services in sheltered housing may imply it is not appropriate for people with dementia. Furthermore, the shift towards teams of ‘floating’ or peripatetic support workers covering several schemes may mean people with dementia are left without on-site support for extended periods (HAPPI, 2009). There is also some research, as well as anecdotal evidence, suggesting that some schemes have faced problems between residents with dementia and other residents (O’Malley and Croucher, 2005) and that the age of much sheltered housing may mean it is not well-suited to older people and people with dementia.

### 3.4.2.2 Housing with care

Over the past couple of decades there has been an expansion in housing with care. There has been significant support and emphasis on the expansion of housing with care, both by researchers (Reynold, 2005) and also in strategies across the UK. The extent to which housing with care schemes have developed has varied across the UK. In England, the Department of Health, supported by the Homes and Communities Agency (HCA), provided £227 million capital funding (2004–2010) to help instigate a market of housing with care properties, with some areas strongly prioritising the development of schemes. Similarly in Wales, the Welsh Government has made significant investment in housing with care schemes.

Recent research suggests many housing with care schemes have large minorities of residents with dementia (ILC-UK, 2011). There have been some specific studies looking at prevalence of dementia. A randomised control sample by the University of Bradford into residents for the

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ExtraCare Charitable Trust found that around 30% of residents in extra care housing will experience significant mental health problems, most notably depression and dementia (Brooker et al, 2009).

A 2009 Personal Social Services Research Unit (PSSRU) study of those moving to extra care schemes found on average 37% had a form of cognitive impairment. However, this included people with mild cognitive impairment as well as those with dementia (Darton et al, 2011). The HDRC roughly estimate around 20% of residents in members' properties have a form of dementia (HDRC, 2011).

Housing with care is often seen as a potential and preferable alternative to admission to residential care homes, since care is available on-site, but people with dementia's independence is maintained and supported (Kopetz et al, 2000; Clarke, 2004; ILC-UK, 2011; Darton et al, 2011). A 2006 review by the Housing Corporation (now the Homes and Communities Agency, HCA) and Housing 21 found extra care facilities provided good quality care to the majority of residents with dementia (Valleley et al, 2006). Recent reviews by the International Longevity Centre (ILC) and PSSRU have found benefit from extra care housing in terms of reducing falls, improving quality of life and reducing admissions to care homes (ILC-UK, 2011; Darton et al, 2011).

The University of Bradford study of ExtraCare Charitable Trust's Enriched Opportunities Programme (EOP) found that people experiencing mental health problems could continue to enjoy a good quality of life and reduce a health intervention 'upstream'. Specifically, the outcomes for people with dementia were that they were:

- half as likely to have to move out into a care home
- far less likely to spend time in hospital as an in-patient
- more likely to have a GP visit
- more likely to see a community physiotherapist, occupational therapist and chiroprapist
- more likely to have their mental health problems diagnosed (Brooker et al, 2009).

While there have been concerns expressed about the cost efficiency of housing with care (O'Malley and Croucher, 2005), both the ILC and the PSSRU studies have suggested housing with care is cost effective, alongside being associated with improving quality of life (ILC-UK, 2011; Darton et al, 2011).

Despite this support for housing with care, there have been challenges and concerns voiced about its role in supporting people with dementia. These include social isolation of residents with dementia and the relationship between residents with dementia and those without (Dutton, 2009).

There are also issues relating to mental capacity and tenancy of properties. While families or carers of those lacking capacity may be able to sign tenancy or leasehold agreements on their behalf, it cannot be ensured that the tenant lacking capacity understands and can comply with terms of the tenancy or lease such as allowing others 'quiet enjoyment' of their properties. This raises questions as to whether tenancy agreements should be offered to those lacking capacity (Dow, 2006; Garwood, 2006).

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Risks have also been voiced that support in housing with care may become fragmented because of a shift towards greater use of personal budgets to fund social care. There is a fear this shift may reduce the flexibility and responsiveness of care available in housing with care schemes, which is so important for supporting people with dementia (NHF, 2010).

Where participants with dementia lived in housing with care, they expressed significant positive responses about these schemes, both because of additional support and also because of the freedom and independence such schemes afforded individuals.

**‘I think its great here. Extra support is there if you need it; if anything goes wrong. This is a good move.’**

**Carer of person with dementia in rented housing with care**

**‘It’s peace and quiet and everything. You make your own stuff and I can go down the town if I want to.’**

**Person with dementia in rented housing with care**

**‘This environment suited me very well...and there is care there at the end of the day.’**

**Person with dementia in rented housing with care**

There is clear support for housing with care and evidence that housing with care can have significant benefit to some people with dementia and may fill a gap between mainstream housing and long-term care in care homes. However, housing with care will not be a viable option for all people with dementia. Some people with dementia may benefit more from staying in their existing property, while others may benefit from, or prefer moving directly into a care home. In addition, some people may have needs too severe to qualify for housing with care and need residential or nursing care, either because of their dementia or because of other health conditions or care needs.

### 3.5 Conclusions

These findings indicate people with dementia and their carers have varied and personal views on whether they wish to remain in mainstream housing or move to specialist housing, but show clear support for people continuing to own their own home.

The views of participants clearly underline the important role housing with care can play in supporting people with dementia, with many respondents expressing support for these models of housing. The development of housing with care models should continue and there is clear desire for models based around owner-occupation alongside schemes where occupation is under tenancy. Furthermore, people with dementia, their carers and families should be informed of housing with care options in their area.

However, other participants have expressed strong support for remaining in their own mainstream homes in the community. Specialist forms of housing therefore cannot be the only solution to supporting people with dementia to remain in the community. Adaptation, information and support services for people living in mainstream housing will be essential to meeting the challenge of supporting people with dementia in the community.

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## Recommendation 2

There should be a choice of housing options and tenures available to people with dementia, including mainstream and specialist housing.

- Local authorities should work with housing developers and housing associations to ensure a mixed economy of housing options.
  - Housing should be available on a range of tenures, including owner-occupied specialist housing.
  - More research should be commissioned into housing and dementia, including housing with care. Research should consider the pros and cons of models of housing, including investigating the limits of housing with care as an alternative for people with dementia.
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## Case study – housing with care

### Opening doors to independence

Housing 21, with funding from the Housing Corporation and in partnership with the University of the West of England, Bristol and Dementia Voice (part of the Housing 21 group), undertook a three-year tracking study to explore what happens to people with dementia living in housing with care, such as extra care housing.

The resultant research report, *Opening doors to independence* (Vallely et al, 2006), found that:

- Extra care housing has a key role in maintaining the independence and health of people with dementia.
- With the right support, people with dementia and memory problems are able to live independently in extra care housing for nearly as long (around two years) as people without significant cognitive impairment.
- Older people with dementia – and their families – choose extra care housing because it meets their needs and aspirations better than other accommodation options.

This is the first long-term study into the contribution extra care housing can make to the care and support of people with dementia and is unique in capturing the views of older people themselves. Therefore it is an important report for everyone concerned with developing services and housing which meet the aspirations of older people themselves.

# 4 Information and adaptations

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## Summary

- Information and advice on housing is crucial to people with dementia making informed choices about housing, but they can struggle to get the information they need.
- People with dementia often use informal pathways for accessing information on housing and often do not differentiate between different providers of information, or between information on housing and information on social care services.
- People with dementia and their carers often access adaptations, and satisfaction levels with these are very high.
- There are a range of sources of funding for adaptations to people's own homes, most prominent of which are disabled facilities grants (DFGs). However, there are concerns that this money might not be spent on adaptations while local council budgets are under such pressure.

## 4.1 Introduction

Given the important role that housing can play in supporting people with dementia, the provision of information and advice around housing is of key importance. Similarly, the strong support expressed by some respondents to remaining in their own homes underlines the importance of access to adaptations, alterations and funds to enable people to have these made.

This section looks at experiences in terms of access to information and adaptations. It does not deal in detail with forms of assistive technology (AT) the Society's position on AT can be found on our website, [alzheimers.org.uk](http://alzheimers.org.uk)

## 4.2 Information and advice

There are potentially a wide range of choices that individuals can take regarding their housing, either in terms of additional housing options or information on adaptations they may wish to have made. Access to information and advice and low-level support is therefore essential to support people with dementia to remain independent in their own homes and enjoy a good quality of life. It is widely accepted in government strategy that early intervention and low-level support, including information, has the potential to result in savings from across health and social care. This could potentially include reducing NHS costs and delaying the need for long-term care (Banerjee, 2008; DCLG, 2011, National Audit Office, 2007; The Marmot Review, 2010).

### 4.2.1 Issues and challenges with access to information

People with dementia and carers often struggle to access any form of information and advice. Alzheimer's Society's Support. Stay. Save. report found only a third of respondents said the person with dementia and their carer were given enough information on free information and support (Alzheimer's Society, 2011).

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There is only limited information specific to housing and dementia. Alzheimer's Society produces factsheets with information on adaptations and other issues relevant to housing (available on the Alzheimer's Society website, alzheimers.org.uk). More broadly, the FirstStop online and helpline service provides information on housing, finances and care to older people (FirstStop, 2012). FirstStop is funded by the UK government and several charities and the DCLG housing strategy has committed to further investment in the service (DCLG, 2011).

Criticism has been levelled that much information on housing is only available online. The Local Government Group highlighted this in Good homes to grow old and suggested more needs to be done to develop printed information that may be more accessible to older people (LGG, 2010).

Most EoH respondents reported they had accessed information through word of mouth, rather than through formal information pathways, and few differentiated between different providers of information.

**'A friend introduced me to [the scheme]. He saved me a book and I looked at it and thought "that's for me."'**

**Person with dementia in specialist housing**

**'I have a daughter who works in community services and she keeps me informed and all that.'**

**Carer of person with dementia in mainstream housing**

**'I know more from my friend than I know from any OT [occupational therapist] or anyone.'**

**Carer of person with dementia in mainstream housing**

Some participants in the EoH research said they found challenges in accessing information and advice.

**'There's so many things out there you have to learn about and apply for. It's a learning curve.'**

**Carer of person with dementia in mainstream housing**

**'I rang the social services, but they weren't interested, at least that's the feeling I got. So I'm no further on in terms of social workers.'**

**Carer of person with dementia in mainstream housing**

Local authorities' social services may be an early point of call for many seeking advice or information on care and support as well as housing and housing options. However, initial contact services provided by local authorities vary considerably, despite all local authorities being required to commission or provide universal information and advice services. A recent Independent Age report found the majority of councils were at best performing averagely when responding to 'first contact'. Independent Age's report was based on unpublished evidence from a CQC 'mystery shopper' review of local authority responses to initial requests for information and advice (Independent Age, 2011).

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Moreover, and specific to housing, social services advice services may not necessarily know what housing options or services exist in their area as their knowledge may primarily relate to care services.

Home-Improvement Agencies (HIAs) can also play a vital role supporting older people to remain independent at home. HIAs, and some local not for profit organisations, assist vulnerable homeowners and private sector tenants to repair, adapt or improve their homes. There are around 210 HIAs in England and 85% of UK residents have access to an HIA (Foundations, 2012). Services provided by HIAs vary across the UK, but they include providing advice on options or local builders, liaising with those carrying out work and helping people obtain other support services.

In addition, HIAs often provide handyman services aimed to support people with basic level repairs and tasks, such as changing light bulbs, which older people may struggle to carry out safely. The England Housing Strategy sets out plans that £51 million will be directed to fund handyman services between 2011 and 2015 (DCLG, 2011). Strategies in Wales and Northern Ireland also highlight the importance of these forms of services.

Staff working in the housing sector are in an excellent position to provide information and advice to people with dementia and their carers. However, they need to have both a good understanding of dementia and awareness about local options in terms of services and resources.

### 4.3 Adaptations and alterations

There is a wide range of adaptations and alterations people can make to their homes to ensure they are better suited to accommodating the needs of people with dementia. In the context of housing, assistive technology and home adaptations can play a vital role supporting people with dementia to remain independent in their own homes.

The Society's Support. Stay. Save. report found significant numbers of respondents reported adaptations had been made in the home of the person with dementia. 40% of respondents said the person with dementia had had adaptations in their home, making them one of the most frequently reported services accessed. Furthermore, respondents reported high levels of satisfaction with these adaptations. 42% of respondents who had an adaptation were very satisfied and 37% were satisfied. Only 17% were dissatisfied or very dissatisfied (Alzheimer's Society, 2011).

Support. Stay. Save. did not investigate what forms of adaptations people had had to their homes. EoH participants who had had adaptations stated these were often concerning bathrooms and stairs, mirroring the problems participants identified with mainstream housing in Section 3.4.1 above.

**'Neither the person I care for or myself could get in the bath, but we didn't get any help.'**

**Carer of person with dementia in mainstream housing**

**'He got stuck in the bath one night and I couldn't get him out.'**

**Carer of person with dementia in mainstream housing**

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**‘Sometimes I would have to go into the shower and have her follow me.’**

**Carer of person with dementia in mainstream housing**

**‘He’s getting very slow. What would happen in the case where he couldn’t get up the stairs?’**

**Carer of person with dementia in mainstream housing**

Some respondents to research reported challenges getting access to the appropriate types of adaptation or the forms of adaptation they wanted.

**‘They were coming out to see about [the front steps] to get a ramp or something. I think it was quite some time, six or seven months [before they came out].’**

**Carer of person with dementia in mainstream housing**

**‘We’ve been trying for the past year to get a shower, and it is very difficult. It’s passed, but we keep on phoning the housing association and they say we will send someone out, but they never do.’**

**Carer of person with dementia in mainstream housing**

However, several respondents expressed high levels of satisfaction with adaptations they had had made.

**‘We’ve got pretty much everything we would need. Handrails on the shower and the like.’**

**Carer of person with dementia in mainstream housing**

Most people who had experienced adaptations to their own homes obtained these through the support of an occupational therapist accessed through their social worker. There was value placed on the support provided by occupational therapists.

**‘I had an OT in and she put a shower seat on the wall and a jump seat on the toilet. The jump seat was fantastic.’**

**Carer of person with dementia in mainstream housing**

**‘The OT came out and did everything and got everything sorted out. It was good.’**

**Carer of person with dementia in mainstream housing**

Alzheimer’s Society’s position statement on assistive technology identifies that, while technology can be beneficial to supporting people with dementia, it has to be tailored to their need and should be put in place early in the person’s condition.

#### **4.3.1 Sources of funding adaptations**

Funding of adaptations and alterations can come from a range of sources. This may include state funding in the form of a state funded social care package, potentially via a personal budget or direct payment. Funding could also come from the NHS as part of a reablement or intermediate care package.

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In England and Wales, local authorities also have discretionary powers to provide financial and other assistance to people making repairs, improvements and adaptations to their own homes. Such grants are administered by the Housing Executive in Northern Ireland. Under these powers local authorities can offer support to social housing tenants, owner-occupiers as well as private and social landlords. People with dementia and carers may also fund adaptations themselves, either as part of a self funded social care package or completely independently and may qualify for severe disabled person relief from VAT (value added tax) for adaptations and equipment.

In addition, local authority and housing departments in England, Wales and Northern Ireland administer disabled facilities grants (DFGs), which are means tested grants to help meet the cost of adapting a property to the needs of a disabled person. These are delivered through a range of providers, but in England half are delivered by HIAs. By 2013/14, DFG funding will stand at £185 million (DCLG, 2011).

EoH participants had mixed experiences of gaining funding for adaptations. Some had been offered no, or only limited, funding.

**‘We had to put a walk-in shower in. But I had to pay for that myself.’**

**Carer of person with dementia in mainstream housing**

However, others had obtained funding.

**‘The OT did it all. We didn’t have to pay.’**

**Carer of person with dementia in mainstream housing**

Although DCLG has committed to invest more funding in DFGs, concerns have been raised about ongoing funding for adaptations. As part of the 2010–14 Comprehensive Spending Review, the coalition government announced reductions in local authority grant funding and removed ring fencing around funding such as that allocated to DFGs (HM Treasury, 2010). In addition, funding for some schemes such as Care and Repair, England’s grant and loan scheme, was heavily reduced.

The APPG HCOP outlined concerns that these steps are a threat to the funding of adaptations and alterations in people’s homes. The group state there is evidence not all money for DFGs is directed to fund adaptations and there is a concern people in lower incomes in their own homes will be unable to access funds to pay for alterations to their homes. They also cite rising demand on home adaptation services provided by charities and benevolent funds (APPG HCOP, 2011).

In addition, ring fencing around Supporting People funding in England has been removed, with the government intending to provide local areas with greater flexibility in how they allocate this funding. Supporting People funding was developed in 2003 to provide housing support and information to vulnerable people. It was provided as a ring-fenced grant to local authorities (ODPM, 2004) and some local authorities have used this money to fund adaptations. There are concerns the removal of the ring fence on this funding will mean reductions in funding for adaptation and information services (APPG HCOP, 2011). In Wales, Supporting People funding is still ring fenced.

The APPG HCOP also raised the challenge that funding for adaptations often comes from housing budgets, but savings resulting from these adaptations are made in the health and social care systems. They report there remain problems unlocking NHS funding to fund adaptations and, where this has happened, it has been largely opportunistic (APPG HCOP, 2011). These findings are broadly supported by the NHF in *Breaking the mould* (NHF, 2011).

## 4.4 Conclusions

The importance of word of mouth for obtaining information on dementia underlines the role of local sources of information and advice on housing and housing options. However, evidence from EoH participants suggests provision of information on housing to people with dementia and their carers is fragmented and variable. Given the importance some participants place on housing in supporting them, consideration needs to be given to how to improve provision of information on housing to people with dementia.

Findings from this research support previous evidence around the potentially important role that adaptations and alterations can play in supporting people with dementia in their own homes. Given this potential, it is likely that coming years will see continued growth in demand for adaptations and alterations for people with dementia and local authorities must prioritise investment in this area.

The Society has concerns that in the face of overall cuts to local authority funding, actual spending on DFGs and other local authority budgets for funding adaptations may fall. Given existing evidence on the value of adaptations and low level interventions, reductions in spending on these services are likely to have negative consequences in terms of supporting people with dementia in their own homes. It is also likely they will burden the NHS and care services with higher costs through increased admission to hospitals and long-term care.

### Recommendation 3

People with dementia, their families and carers, should have access to information and advice on housing options, handyperson services and sources of funding for adaptations and alterations.

- People with dementia and their families should be provided with information and advice on housing and housing options from the point of diagnosis.
  - Staff working in housing should be trained in understanding dementia and supported to provide information on local services and housing options.
  - Local commissioners should ensure first contact services are able to provide advice and information on housing and housing services, alongside information on social care and third sector services.
  - Local authorities ensure all funding for disabled facilities grants (DFGs) is allocated for this purpose and ensure they utilise discretionary powers to provide adaptation, information and low level support services.
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## Case study – adaptations services

### Riverside Home Improvement Agency

An innovative project to help people with dementia live safely in their own homes for longer and reduce the need for antipsychotic drugs has been developed by Riverside Home Improvement Agency (HIA) in Liverpool.

The HIA team retro-decorate people's homes – helping them choose vintage furniture and items that bring back memories of happy times – such as old transistor radios, 1960s holiday posters or mid-century chairs. Familiar objects can make people feel calmer, meaning there is less requirement for medication. They also help individuals to remember their daily routine – such as sitting down for a meal.

Riverside HIA Liverpool also use simple interventions such as fitting open-fronted drawers, glare-free lighting, re-organising mirrors and putting coloured tape up and down stairs. This supports people with dementia who are sensitive to lighting glare and mirrors, have difficulty with depth perception, have difficulty climbing the stairs, and who may forget tasks such as where clothes are stored or when to make meals.

The scheme is proving effective in helping people with dementia to live in their own homes for longer and manage daily tasks, bringing them out of a state of withdrawal and improving their socialisation – all of which reduces the need for residential care or hospital admission.

For more information, see [riverside.org.uk/corporate/news\\_and\\_press\\_office/riverside\\_view/dementia\\_proofing.aspx](https://riverside.org.uk/corporate/news_and_press_office/riverside_view/dementia_proofing.aspx)

# 5 Principles of design

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## Summary

- Design of housing and the wider environment can play a key role in ensuring people with dementia enjoy a good quality of life.
- The issue of design and dementia is receiving growing prominence, with the publication of design principles, guides and guidelines covering homes, care environments and the wider environment.
- Challenges remain in the adoption and uptake of design principles and guidelines, as well as ongoing research challenges to understand what forms of design work best.

## 5.1 Introduction

Good quality design has the potential to be empowering and support people with dementia to remain independent and live at home for longer. Design is broader than simply the layout of new homes, covering alterations and furnishings that individuals can make to make existing homes more suitable for people with dementia. This section briefly covers the key guidelines that exist for design and dementia.

## 5.2 Design for older people

There is significant evidence about how design can support older people. Examples include the evidence laid out in the HAPPI report (HAPPI, 2009), guidelines formerly from the Commission for Architecture in the Built Environment (CABE, 2010), guidelines in the WHO Age Friendly cities guide (WHO, 2007) and the Royal Institute for British Architecture guide for assisted living (RIBA, 2011).

The HAPPI report identifies ten key design elements for building future homes to meet the need and aspirations of the ageing population:

- space and flexibility
  - daylight in the home and in shared spaces
  - balconies and outdoor space
  - adaptability and ‘care ready’ design
  - positive use of circulation space
  - shared facilities and ‘hubs’
  - plants, trees, and the natural environment
  - energy efficiency and sustainable design
  - storage for belongings and bicycles
  - external shared surfaces and ‘home zones’ (HAPPI, 2009).
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Other guidelines include the EVOLVE tool, developed by the University of Sheffield and the PSSRU, which is a tool for evaluating the design of older people's housing. EVOLVE sets out checklists relating to how buildings and rooms contribute to physical support as well as to well-being (Lewis et al, 2010). Guidance also exists for specific types of housing, such as the Strategic Housing for Older People (SHOP) resource pack produced for the Housing Learning Improvement Network and the Association of Directors of Adult Social Services (ADASSS) to give guidance on the building and development of extra care housing (Oxford Brookes Institute for Public Care, 2011).

According to the APPG HCOP, design should be more than simply about accessibility and design standards in the home, but also about how to design an age friendly community (APPG HCOP, 2011). The APPG highlighted that many older people value access to local amenities and green space, rather than simply well designed homes.

### 5.3 Design for dementia

There are specific pieces of work focusing on design for people with dementia. These principles cover how buildings should be constructed, interior and exterior design, and adaptations and equipment within homes themselves. Principles of design for people with dementia often focus on clear orientation, memory cues, access to open space and creating a 'homely' environment.

A significant amount of guidance around design for dementia is focused on principles of design for housing with care (Thomas Pocklington Trust, 2010). This includes guidance produced for the Housing LIN by PRP Architects (Nicholson et al; 2008).

Other guidelines have focused on care homes and health settings. These include the Kingston study on care home design (Drake, 2010) and the King's Fund Enhancing the Healing Environment projects (King's Fund, 2011). Guidance for individuals considering how they might adapt their homes has been produced by the Stirling Dementia Centre, whose guides also cover a range of other care settings (DSDC, 2010), and Alzheimer's Society factsheets (Alzheimer's Society, 2012d).

Alongside design of living and care environments, design of the wider neighbourhoods and outdoor environments can have a significant effect on people with dementia. The Oxford Brookes Wellbeing in Sustainable Environments Research Unit published key findings about the outside environment and people with dementia. Key findings of their research included that people with dementia continued to go out alone, many daily, although many limited their activities to relatively undemanding situations (Mitchell and Burton, 2006).

Findings also included that the outdoor environment provided a sense of independence and self-respect to older people with dementia, but that complex, crowded and heavily trafficked places could be confusing. The report stated mixed use, compact neighbourhoods, varied urban and architectural features and pedestrianised streets were preferable to people with dementia (Mitchell and Burton, 2006).

Some guidance has been developed for specific subgroups of people with dementia, most notably people with dementia and sight loss. The Thomas Pocklington Trust's research paper comparing sight loss and dementia guidance found that, while there were common principles between design guidance for people with sight loss and guidance for people with dementia,

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there was potential for conflict, particularly around features and curved, as opposed to straight, corridors and corners (Thomas Pocklington Trust, 2010).

## 5.4 Adoption and use of design principles

The former Commission for Architecture in the Built Environment (CABE) review of design and housing suggested that regulations and guidance on design and housing were complex, with crossover between the two. CABE called for a greater consistency in standards to which homes should be built (CABE, 2010).

Design standards such as the Lifetime Homes standard are an important means by which new housing can be better adapted to the needs of people with dementia (DCLG, 2008). However, the government's housing strategy makes clear those aspects of the Lifetime Homes standard not already included in design regulations will be optional, meaning not all new homes will have to be built to these standards (DCLG, 2011).

## 5.5 Conclusions

A significant amount of guidance has been developed around housing for older people and specifically for people with dementia. However, the focus on specialist housing may mean many people with dementia who wish to remain in mainstream housing may be unable to find even new build accommodation built to high-level standards.

### Recommendation 4

People with dementia should have access to homes designed with their needs in mind.

- Homebuilders should consider existing design principles when developing new housing, especially housing aimed at older people.
  - All new housing should be built to the Lifetime Homes standard.
  - Further research should be carried out into the preferences and needs of people with dementia in terms of housing and wider environmental design.
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