

# Being Home

## Housing and Dementia in Scotland Key Findings

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# 1. Introduction

'I do the same things. I go out to the garden, work away in the garage, things like that, I'm very active. As far as I am concerned I have dementia and I can't stop it, but don't like it stopping me either.'

**Angus** who lives with dementia

Scotland has been at the forefront of rights based care and has led the way in policy and legislation to support and protect the person living with dementia. Appropriate housing that will meet current and future needs of the person living with dementia, their family and supporters, is a fundamental right and concern. However, despite Scotland's leadership in living well with dementia, there is still some way to go to address key concerns in this area.

There are approximately 90,684 people living with dementia in Scotland (Alzheimer Scotland, 2017). Information about the role of housing services in dementia is limited, yet the escalating drive for the person living with dementia to remain at home has made involvement of housing and housing related staff essential. The focus of this report is to provide a comprehensive overview of the current housing situation for people affected by dementia including a range of housing options, possible solutions, services and supports.

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The Life Changes Trust and Angus Care and Repair commissioned this report, funded by the Life Changes Trust, from University of the West of Scotland and Partners. This report is a combination of desk based research methods to review current practice, services and policy and new interview based evidence from policy makers, health and social care practitioners. Capturing the voice of people with dementia involved engaging with groups attending Alzheimer Scotland dementia cafes, including carers.



## 2. Policy in Scotland

### 2.1. Key findings

- Distinct and independent policies and guidance are available in Scotland about housing and dementia. These state the importance of each topic, but all lack detail about what should be done.
- Housing and planning guidance contains some consideration about meeting the needs of an ageing population, but few reference people living with dementia.

### 2.2. Our evidence

There are very few references to dementia in Scottish housing planning policies or guidance, despite the current emphasis on supporting the person with dementia to remain in their own home for as long as possible.

To date the Government's Dementia Strategy documents emphasise independent life at home as vital, however they lack specific detail related to housing and focus on care provision rather than setting.

Planning guidance and policies about older people and people with dementia take a reactive approach aimed at providing services and equipment at the point of need. Advanced planning for future housing needs is not currently routine practice within Scotland.

### 2.3. What should happen

- Housing and dementia needs to be proactively aligned within policy discussions and decisions.
- Recognition should be given to housing and dementia at all levels to guide integrated services and partnerships.
- Housing should be closely integrated into advance planning processes about the future needs for the person living with dementia.



Advanced planning for future housing needs is not currently routine practice within Scotland.

## 3. Housing in Scotland

### 3.1. Key findings

- A higher proportion of Scotland's older people live in owner occupied than in social housing.
- There is concern that much of this stock has high levels of disrepair and poor energy efficiency.
- There is a dearth of suitable accommodation appropriate to the diverse needs of people with dementia.
- Planning and building regulations currently do not support development of housing and services to meet the needs of the ageing population and in particular people living with dementia.

### 3.2 Our evidence

In Scotland around 17% of the population is aged 65 years and older and 4.4% of the population is aged 80 years or above. Almost 75% of people 65 years and older live in owner occupied housing. Some 41% of all Scottish households with a head of household aged 65 years or older live alone.

Housing conditions for many older people are generally poor, particularly in rural locations. 74% of people aged 65 years and older live in housing that is regarded as having some level of disrepair (Scottish House Condition Survey 2012-2014). Some 13% are deemed to live in housing that is

'unhealthy, unsafe and unsecure'. Poor housing conditions intensify the level of risk for people living with dementia.

There is an imbalance in housing provision across all tenures. According to the Scottish Government's Housing Key Data, there is a total of 2,013 Scottish housing facilities for older people with only 7% of those facilities for private purchase. The lack of new private purchase provision for older people highlights a gap in the market that is currently not addressed. Provision of housing for older people by local authorities and housing associations has shown little increase in the last 10 years and there has been a reduction in sheltered housing provision.

Spatial planning and housing policies have minimal reference to the needs of people with dementia, despite the enthusiasm for dementia friendly design. Plans for dementia specific policies have not yet been put into action.

### 3.3. What should happen

- Housing policy and planning should consider the development for all age housing suitable for changing needs through life.
- Some increase in new build private housing that is suitable and easily adapted to support older people and people with dementia is urgently required.
- Specific spatial planning policies should be developed to reflect the needs of people with dementia.



# 4. Innovations in housing

## 4.1. Key findings

- There are numerous examples of good practice in housing and dementia, in Scotland and further afield, that could be implemented and developed.
- Housing associations lead in the development of innovative approaches, but this could be more effectively disseminated and replicated.
- Information about good design for housing for the person living with dementia is available, but not sufficiently accessible for the general population.

## 4.2. Our evidence

There is a range of good design guidance for housing suitable for people with dementia. Examples include:

- Dementia Services Development Centre (DSDC), Joint Improvement Team (JIT), Chartered Institute of Housing (CIH) and University of Stirling (2013). Improving the design of housing to assist people with dementia: <http://www.jitscotland.org.uk/resource/improving-housing-design-assistdementia/>
- The Thomas Pocklington Trust (2014) Design Of Homes And Living Spaces For People With Dementia And Sight Loss: A Guide: <http://www.pocklington-trust.org.uk/project-design-of-homes-and-living-spaces/>

- Halsall Lloyd Partnership (2015) Design for Dementia Guide. This provides an illustrated guide for interior and exterior housing needs. [http://www.hlpdesign.com/images/case\\_studies/Vol1.pdf](http://www.hlpdesign.com/images/case_studies/Vol1.pdf)

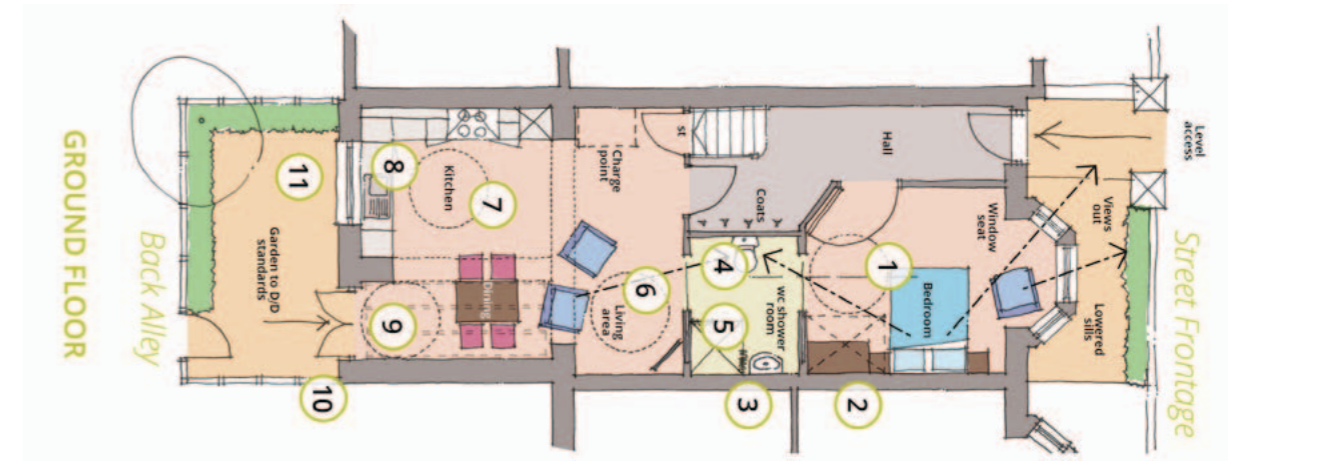
Positive design principles could be applied to specialist residential care schemes or retrofit of existing dwellings as in the Victorian Terraced House design opposite.

At same time there is a lack of provision and research into models of new housing for those people with dementia (Housing Options for People with Dementia Report, Dementia Care, 2015). Such housing models may include independent living but with shared communal facilities; extra care housing with a share of the accommodation designed for people with dementia; or close care housing within the grounds of a residential or nursing care home.

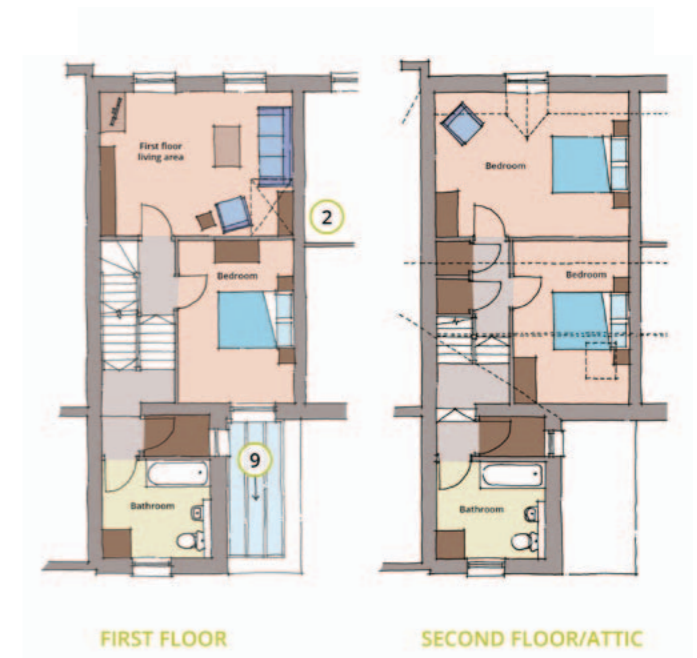


There are numerous examples of good practice in housing and dementia, in Scotland and further afield, that could be implemented and developed.

Picture courtesy of Bill Halsall of the Halsall Lloyd Partnership and Dr. Rob MacDonald of Liverpool John Moores University. (Copyright Halsall Lloyd LLP)



- 1 hoist position
  - 2 knock through panel in floor for possible future lift
  - 3 bathroom to disability standards
  - 4 wc and wet room - visible from bed position and living area
  - 5 walk in shower
  - 6 continuous floor - equal light reflectance value (LRV)
  - 7 kitchen/dining area, open plan
  - 8 kitchen with open shelving and glazed door/cupboard fronts
  - 9 glass roof side extension - admitting natural daylight to open plan, living/dining/kitchen area
  - 10 access to garden with level access
  - 11 raised planting beds
- wheelchair turning



## 4. Innovations in housing



*Croftspar Glasgow*

There are an increasing number of small-scale examples of innovative provision, mainly situated within the social housing sector. These include:

**Croftspar Glasgow:** is a partnership project operated by Alzheimer Scotland and owned by Cube Housing Association. This facility, described as 'enhanced sheltered', provides eight one bedroom bungalows with on-site extra care being provided.



*Loretto Care Glasgow*

**415 Hub Innovation Project:** Loretto Care, Glasgow. This project, established in 2013, aims to support older people to stay in their homes for longer. A demonstrator flat is available to introduce a range of adaptations that could meet their future needs.

**Viewpoint Housing Association:** supported by Stirling University Dementia Services Development Centre (DSDC), has created two dementia friendly flats to illustrate a range of design features.



*Viewpoint Housing*

International innovations in housing are an important source of inspiration, examples include, the Hogewyck development near Amsterdam. This is called a 'dementia village' and is a diverse urban setting with blocks of housing reflecting different living situations: <http://hogeweyk.dementiavillage.com/en/l>.

In Japan, the Tsudoi-ba, or open house, depends upon access to relatively inexpensive, empty houses, used by members of the local community to provide support for people with dementia and carers: [http://www.housinglin.org.uk/\\_library/Resources/Housing/Practice\\_examples/Housing\\_LIN\\_case\\_studies/HLIN\\_CaseStudy\\_105\\_Japan-Grassroots.pdf](http://www.housinglin.org.uk/_library/Resources/Housing/Practice_examples/Housing_LIN_case_studies/HLIN_CaseStudy_105_Japan-Grassroots.pdf).

Australia's Transition Care Program (TCP) is a joint Commonwealth-State initiative that provides short-term restorative care for older people after a hospital stay: <http://www.amanaliving.com.au/dementia-care/dementia-transition-care>

In Scotland, information on undertaking adaptations or moving to more suitable accommodation is recognised as being important, but evidence suggests that such information is difficult to access. Housing support is generally available within social housing, but this can be limited and generally only available at the point of need.

There are ways to provide information and advice on housing and dementia to the wider population. A web based housing portal has been devised as part of this report and developed by the BRE group. The sample website can be viewed at: <http://bregroup.com/dip/>

**'There is so little information up front. There is no one to ask really, everything happens through the day and if you work it doesn't happen.'**

**Elaine**, family carer

### 4.3. What should happen

- Design principles for dementia should be part of planning for all new buildings and retrofit activities.
- Dementia focussed innovations in housing should be considered for wider application both in the private and public housing developments.
- Information about design and dementia should be easily accessible to the general population and all those affected by dementia.



# 5. Information, knowledge and collaboration

## 5.1 Key findings

- Those who work within housing services, including practitioners, support and maintenance staff, identify gaps in their knowledge about how to support a person with dementia and their family.
- Very little is known about the knowledge and awareness of dementia among providers of housing related services in the private sector.
- Collaboration within health and social care integrated teams is not fully realised or inclusive of the housing contribution.
- Currently, people living with dementia and their family lack information about general housing advice, support and funding.

### Practice point

A group of practitioners in a North Lanarkshire Health and Social Care Partnership area, including health, social care and housing, meet six weekly to discuss issues affecting older people living in their catchment area who have long term conditions, including dementia. They are able to proactively address concerns raised by any member of the group and find solutions together. This has led to anticipatory arrangements that allow better outcomes for the person and allow better planning for housing adaptations and support.

## 5.2. Our evidence

A recent survey report commissioned by CIH Scotland, from Arneil Johnston, (2017) identified that 55% of front line housing staff lack confidence in their knowledge about dementia. Crucially, almost 97% agreed that housing has a key role to play in supporting the person affected by dementia.

Very little is known about the knowledge and awareness of the diverse group of people providing services to people living in owner occupied housing. Current initiatives to raise awareness, such as Dementia Friends, Dementia Friendly Communities and campaigning work by organisations such as Alzheimer Scotland may not as yet have sufficient reach for this group of people. Care and Repair organisations are available in 31 of the 32 local authority areas

and can provide independent information about home assessment and sources of funding. However, funding for these services are often not given high priority by Local Authorities, which may limit their impact.

Many of the people we spoke to in the preparation of this report highlighted that housing has a specific contribution to make within the new Integrated Joint Boards. In practice this is not yet fully realised or implemented in all areas.

There are inequities in the funding of home adaptations between tenure types, and people with dementia and their families are often unsure of funding options available to them. There is also a variance in clear support and guidance for people with dementia and their families about the assessment and funding of home adaptations in all housing tenures.



Housing and housing services have a crucial role to play in supporting the people affected by dementia.

## 5.3. What should happen

- The recommendations of the recent CIH funded report, about the role and educational needs of housing staff, should be implemented.
- National awareness campaigns about dementia should specifically include those who work in housing related occupations.
- Integrated health and social care partnerships should review and consider the involvement of social and private housing representatives.

# 6. Adaptations and technology

## 6.1. Key findings

- Given the current lack of suitable housing supply, it is important to consider how to adapt existing housing stock to meet the needs of people with dementia, across all tenures.
- All home adaptations should be considered as early as possible, to ensure the needs of people with dementia are person centred, well planned and can promote living well at home for as long as possible.
- Home adaptations should address the cognitive and psychological needs of people living with dementia as well as physical support.
- The role of technology to support people with dementia at home is important. However technology is advancing rapidly and people with dementia need to be supported to adapt and use mainstream technology.

## 6.2. Our evidence

Due to the limited level of housing stock suitable for older adults with dementia, it is important to adapt current living environments to ensure homes are safe and enabling. There are a number of Dementia Friendly Design guidelines outlining how to design living spaces that can maintain the independence of people with dementia. Currently, most home

adaptations are a response to physical needs, for example wet room showers or rails, and not directly related to dementia. However, there is some indication that this is beginning to change:

**Things are changing, recently I had an Occupational Therapy assessment asking for a walk in shower and it was really detailed. It asked for non-reflective surfaces and bright colours for grab rails. It actually makes it easier to get it right.**

### Care and Repair staff

There is a growing awareness of the usefulness of telecare, telehealth and assistive technology in supporting people with dementia in their own homes. Telecare services have been shown to be successful in supporting people with dementia and reducing both hospital and care home admissions. The use of everyday technology available in smart phones and tablet computers is becoming popular and increasingly accessed by people with dementia. However, there is a lack of recognition in policy, strategy and practice, that people with dementia are more likely to use their own technology and create their own solutions. It is clear that the support for mainstream use of technology is not yet widespread.

It is important that home adaptations are person-centred, well planned and timely for the family, whether these are physical or technological based adaptations.

These will be more successful if developed in collaboration with the person, their family and healthcare and housing professions. Advice and information on housing options and adaptations should be provided from the point of diagnosis and an early assessment of need for future planning is important to increase the success rate of interventions.

## 6.3. What should happen

- Planning for adaptations should focus on prevention, recognition,

### Practice point

The Dementia Enablement Service, funded by the Life Changes Trust, is a pilot project in Aberdeen, Angus and Lochaber, Lochalsh and Skye and assists people living with dementia to remain independent. The service provides housing advice, support and funding to enable people living with dementia to remain at home for as long as possible. The dementia informed officer takes time to get to know the person and carries out a home assessment to see if there are any safety issues or particular difficulties, working with the person to resolve them. People are encouraged to engage in the early stages of dementia, rather than waiting until significant work is required or relocation becomes inevitable. The service has supported over 200 people living with dementia in these three local authority areas in its first year. This innovative project will seek funding to be developed and extended across Scotland.

assessment and intervention for the person at the earliest point possible, regardless of tenure type.

- Easily accessible information, training and support should be available to people with dementia and their families interested in using technology.
- Increasing use of technology should recognise that many people living with dementia already use mainstream digital devices and consideration should be given to ways of supporting this approach, providing bespoke adaptations where necessary.
- Information about home assessment and sources of funding for home adaptations should be transparent from the point of diagnosis.

# 7. Recommendations

## For policy makers:

- Align housing and dementia within policy discussions and decisions.
- Develop specific spatial planning policies to reflect the needs of people with dementia.
- Drive forward the development of all age housing suitable for changing needs throughout life.
- Support innovative housing solutions for people with dementia in private and public housing developments.
- Ensure national dementia awareness and education programmes include housing related occupations.
- Encourage research about the housing needs and experiences of people with dementia, family and supporters.

## For housing sector organisations:

- Increase new build private housing suitable for older people and people with dementia.
- Include design principles for dementia as part of planning for all new buildings and retrofit activities.
- Explore ways to implement housing innovations in private and public housing developments.
- Provide information about design and dementia that is accessible to the general population and all those affected by dementia.
- Implement the recommendations of the recent CIH funded report (2017) about the role and education of housing staff.

## For health and social care partnerships:

- Recognition should be given to housing and dementia, by involvement and partnership with social and private housing representatives.
- Integration of housing in advance planning processes about future needs for the person living with dementia.
- Focus home adaptations on recognition, assessment and intervention for the person at the earliest point possible.
- Increase available information, training and support to people with dementia and their families interested in using technology.
- Provide transparent information about home assessment and sources of funding for home adaptations.



## 8. Conclusion

The person with dementia, their family and supporters need appropriate housing to live well. This is influenced by a wide range of stakeholders from policy makers to front line workers in housing, health, social care and the third sector. However, specific housing and dementia policy is not aligned or integrated. The developing opportunities for leadership around housing from health and social care partnerships should be supported and strengthened.

Housing policy and planning should support an increase in the range of housing options, both public and private, to meet the needs of the person with dementia and their family. Within public and private housing there should be increased choice, not only to support people who wish to move to appropriate accommodation, but also to provide early interventions to adapt the person's current home.

Provision of information and advice is crucial to positive decision-making. This requires development to find ways to make information about housing design, adaptation, technology and support available to the person with dementia, their family and supporters.

Staff within a range of housing related organisations are very well placed and should be appropriately trained to support the person with dementia. Recognising the complexity and diversity of the needs of people affected by dementia, housing should be part of an integrated service playing its role to the full.

This role should form part of a pathway, working with the person from the earliest possible stage, even before diagnosis, then through changes and adaptations over the course of the condition. Part of this role is to respond quickly during periods of sudden change, often related to ill health, where there has to be a co-ordinated and truly integrated housing, health and social care response.

For example when there is an emergency hospital admission or in discharge planning.

This report has sought evidence from a wide range of stakeholders and highlights a lack of research evidence about the needs and preferences of people with dementia, the efficacy of adaptations and support at home and the impact of change and choice of tenure. In order to meet the recommendations suggested within this report, further research is urgently required to fully understand the housing needs and experiences of people living with dementia in Scotland.

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A full report supporting these findings is available at [www.lifechangestrust.org.uk/projects/housing-and-dementia](http://www.lifechangestrust.org.uk/projects/housing-and-dementia) and [www.uws.ac.uk/ascpp](http://www.uws.ac.uk/ascpp)

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