

# Housing and dementia framework

A practice framework to support Scotland's housing sector

October 2019



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# Introduction

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The purpose of this document is to provide a framework for Scotland's housing sector which sets out how best to support people living with dementia and their carers.

It is influenced by the outcomes that people should experience in relation to their housing and a series of commitments for housing organisations to sign up to.

The framework is for:

- social landlords,
- private landlords and letting agents, and
- care and repair organisations.

It will also be relevant to the work of:

- housing advice organisations,
- health and social care partners,
- contractors and companies carrying out work on behalf of social landlords, and
- third sector organisations.

The housing and dementia framework was commissioned by the Place, Home and Housing portfolio of Healthcare Improvement Scotland's Improvement Hub (ihub) with Chartered Institute of Housing (CIH) Scotland and Alzheimer Scotland. Both the ihub and CIH Scotland have continued to support the housing sector to articulate its contribution to supporting people living with dementia to stay at home for as long as practically possible.





## Background

According to Scottish Government figures, 90,000 people are living with dementia in Scotland, a population that is growing older with an increasing risk of developing dementia. Approximately 50% of people over 90 years of age are currently living with dementia.<sup>1</sup> Dementia has now become the second most common cause of death in Scotland.<sup>2</sup> There is an increasing desire to support people living with dementia to self-manage and retain their independence for as long as possible. All the evidence suggests that staying at home helps people living with dementia achieve the best outcomes for themselves in familiar surroundings and where they can maintain connections with community life.

We know that that the majority of people living with dementia stay at home (estimates put this at around 65%) with the remainder either in hospital or in care homes. All recent research on views of people affected by dementia highlights the importance of home as contributing to wellbeing and health. People with dementia live in all tenures.

<sup>1</sup> National Dementia Strategy: 2017-2020, Scottish Government, [www.gov.scot/publications/scotlands-national-dementia-strategy-2017-2020](http://www.gov.scot/publications/scotlands-national-dementia-strategy-2017-2020)

<sup>2</sup> Leading Causes of Death in Scotland, National Records of Scotland, [www.nrscotland.gov.uk](http://www.nrscotland.gov.uk)

Housing is already playing a role creating community anchors all over Scotland and is well placed to contribute to delivering community and housing solutions to support people living with dementia. While there are a number of projects and initiatives across Scotland on housing and dementia, feedback from across the sector and research commissioned by the Life Changes Trust<sup>3</sup> indicated that there were gaps in knowledge and policy alignments as well as a difficulty in articulating housing's role within and outwith the sector. With this in mind two pieces of research focusing on housing and dementia were commissioned in 2016–2017:

- CIH Pathways carried out by Arneil Johnson. This focused on practical examples of housing's role in supporting people with dementia and developed four housing pathways.<sup>4</sup>
- Life Changes Trust: Being at Home, carried out by the University of the West of Scotland. This focused on policy and practice.<sup>5</sup>

Not surprisingly both highlight a similar range of issues in their recommendations calling for:

- The development and recognition of housing's role to support people living with dementia to live well at home.
- Increased collaboration and understanding of housing's role by health and social care partners.
- A skilled and informed workforce.
- The need for housing policy to reflect and recognise the Scottish Government's Dementia Strategy and the contribution housing can make.
- The need for the planning system and building regulations to take account of the needs of people living with dementia.

<sup>3</sup> Housing and Dementia in Scotland, Life Changes Trust, [www.lifechangestrust.org.uk](http://www.lifechangestrust.org.uk)

<sup>4</sup> Dementia Pathways, CIH Scotland, [www.cih.org/media/e5qci4ku/cihdementiapathways-practitioner-guidance-final.pdf](http://www.cih.org/media/e5qci4ku/cihdementiapathways-practitioner-guidance-final.pdf)

<sup>5</sup> Housing and Dementia in Scotland, Life Changes Trust, [www.lifechangestrust.org.uk](http://www.lifechangestrust.org.uk)

The framework has been developed to support housing's contribution as set out in the current National Dementia Strategy and should be read in the context of the Scottish Government's policy framework as set out in *Age, Home and Community: A Strategy for Housing for Scotland's Older People*.



#### National Dementia Strategy 2017–2020<sup>6</sup> | Commitment 12

We will work with national and local stakeholders to implement actions in the refreshed *Age, Home and Community: A Strategy for Housing for Scotland's Older People: 2012–2021* to support people to live safely and independently at home for as long as possible.



#### Age, Home and Community, 2018 Scottish Government<sup>7</sup> | Action 14

The Scottish Government will take action through the National Dementia Strategy to ensure those diagnosed with dementia have access to the right housing and support to enable them to live in their home independently for as long as possible.

<sup>6</sup> National Dementia Strategy: 2017–2020, Scottish Government, [www.gov.scot/publications/scotlands-national-dementia-strategy-2017-2020/](http://www.gov.scot/publications/scotlands-national-dementia-strategy-2017-2020/)

<sup>7</sup> Age, Home and Community: A Strategy for Housing for Scotland's Older People 2012–2021, [www.gov.scot/publications/age-home-community-strategy-housing-scotlands-older-people-2012-2021](http://www.gov.scot/publications/age-home-community-strategy-housing-scotlands-older-people-2012-2021)

## Context

This framework builds on the work already carried out by CIH Scotland to promote dementia awareness and dementia friendly design guidance.<sup>8</sup> The framework will support the promotion, wider dissemination and use of the CIH Scotland's Housing and Dementia Pathways and Practice Guide<sup>9</sup> for the sector and the delivery of the four housing pathways identified through that work:

Pathway 1	Assisting and supporting early diagnosis
Pathway 2	Early assessment of the suitability of someone's home
Pathway 3	Enabling a person affected by dementia to remain or return home quickly
Pathway 4	Ensuring holistic consideration of assistance and support as dementia progresses

## Developing the framework

The housing and dementia framework has been developed in conjunction with CIH Scotland and has drawn on the input and support of a range of key stakeholders to develop the outcomes and commitments and self-assessment template.

We have discussed the framework with a number of key organisations. We have collaborated with and been supported by Alzheimer Scotland. Their key message is the vital importance of involving people living with dementia and their carers in designing and developing policies and services.

We have also looked at the need to consider the different cultures, languages and customs which thrive in our communities in Scotland in designing policies and services. Equality and inclusion should be at the centre of what the housing sector does. This means embedding an understanding of different cultures and what that means for policies, services and practice.

<sup>8</sup> The Dementia Services Development Centre, Stirling University, <https://dementia.stir.ac.uk/housing-dsdc/design-housing>

<sup>9</sup> Dementia Pathways, CIH Scotland, [www.cih.org/media/e5qci4ku/cihdementiapathways-practitioner-guidance-final.pdf](http://www.cih.org/media/e5qci4ku/cihdementiapathways-practitioner-guidance-final.pdf)



In developing the framework, we spoke to people living with dementia, their family members and carers to understand what mattered most to them and learn about their housing experiences. This provided us with powerful insights into people's experience on the ground and we have used that feedback in developing the framework.

In general, participants talked about frustration with the housing system, not getting the advice and information they needed, staff not understanding the issues they faced and having to wait too long for a move to a more suitable home. Here are some examples of the issues people met in trying to find the right home for themselves and their carers:

**Stairs becoming a safety issue and preventing people being able to leave their home leading to loss of independence and social isolation.**

“They don't understand dementia. We are seven floors up and they put strips on the stairs so T could see them but they didn't put them at the edges of the step. The Housing Officer doesn't understand dementia.”

**Lack of understanding or awareness from housing staff, including a lack of understanding about how carers and family members are affected.**

“They need training. We need access to information and we need to know the processes.”

**Lack of flexibility in allocations policies meaning someone might only be eligible for a one bedroom home when they need two bedrooms to support a carer.**

“We were told ‘We haven't let out a house in years’, ‘You are over-housed’ and ‘You will only get a single apartment’. But we need two rooms so I can get a sleep.”

### **Trying to plan ahead but not getting priority to move home.**

“They don't understand dementia because you are not visibly ill. It is so hard trying to plan for the future. That's what we are trying to do like we've been told to do but we can't get a new house until things get really bad and then it will be too late and moving will be worse.”

### **Issues with upstairs flats where mobility was becoming more difficult and potentially dangerous over time.**

“If I could get to the shops myself – I would but I can't get down the stairs and so I can't get out at all. I have a private landlord and can't adapt anything. You have one set day to go and speak to them (housing). There's no appointments and if you don't get to see someone you have to go back next week.”

### **Long waits for housing and not enough information about realistic waiting times.**

“We've been waiting for years, we had five years on the general waiting list and then five years with medical priority and we still don't know how long it will be.”

“Feels as if our hands are tied – it's a waiting game.”

### **Not receiving advice about housing when first diagnosed with dementia.**

“They need to be sorting this out when people first get their diagnosis. Make you feel as if you are still you. You had a worth.”

What people told us clearly demonstrated the need for housing organisations to become more aware of the issues faced by people living with dementia, the kind of support and advice that they need and the needs of their partners or carers.





# The housing and dementia framework

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The personal outcomes identified in the framework have been discussed with people living with dementia and their carers, supported by Alzheimer Scotland and the dementia networks supported by the Life Changes Trust. Everyone we talked to agreed that they cover all of the things they would like to be experiencing but weren't at the moment.

The purpose of the framework is to support the housing sector:

- to develop and improve policies and services for people living with dementia,
- to increase awareness and understanding of people living with dementia for staff and communities,
- to improve joint working with health and social care partnerships to contribute to a holistic package of support for people living with dementia, and
- to develop and promote the housing sector as dementia friendly.

The framework offers the sector an opportunity to:

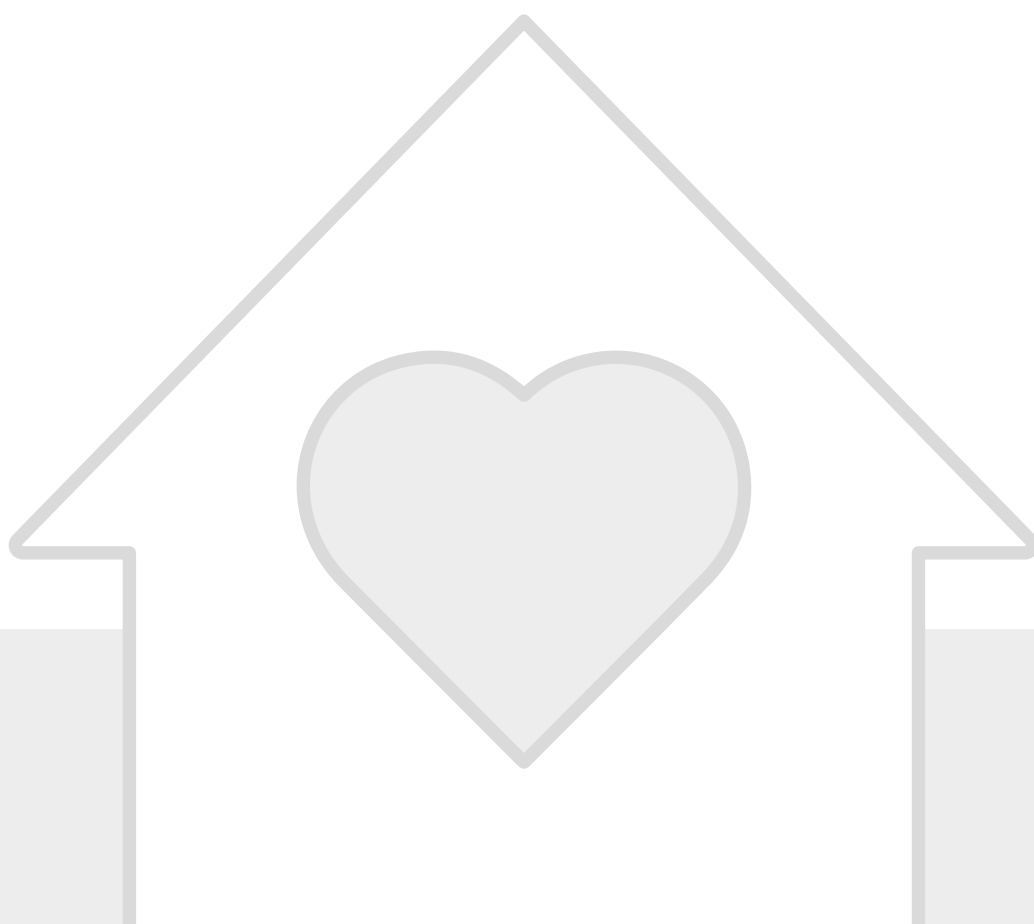
- test current practices, services, policies and partnership working,
- develop an improvement action plan and strategy, and
- share the framework at local and strategic level with health and social care partnerships to improve partnership working, as well as adding to the Housing Contribution Statements.



The framework is made up of three parts:

- A set of outcomes which people living with dementia and their families think are important.
- A series of commitments for housing organisations which support the achievement of the outcomes.
- A self-assessment framework which supports organisations to demonstrate how they are meeting the commitments and/or identify areas where more work needs to be done.

The commitments are action focused and the self-assessment is not prescriptive. It is designed to help housing organisations, their tenants and communities decide on what is most important for them to achieve. Organisations should consider how best to embed the approach and align with their strategic and operational activities.





## How to use the framework

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The framework has been designed to support housing organisations to provide better services for people living with dementia. We are encouraging organisations to sign up and show their commitment by joining our [public register online](#), and sharing information about the commitments and progress towards them with their tenants and communities. We would also like to use the framework as a platform for sharing knowledge and practice with the wider housing sector to help drive improvement. However, you can still use the framework to measure improvement without joining the register.

Housing organisations can engage with the framework on a number of levels:

- Sign up to the outcomes and commitments online.
- Use the framework to test your current service approach and policies.
- Use the framework to develop and improve your service and policies.
- Share the framework at local and strategic level, adding to the Housing Contribution Statement.

The framework:

- is voluntary,
- is flexible and non-prescriptive,
- should capture what is already being done,
- can be tailored to fit the organisation,
- is about improvement and working towards meeting the commitments, and
- will create a platform to share knowledge and practice.

The aspiration articulated in the Scottish Government's strategies is clear that solutions to support people living with dementia to live well and full lives, lies in supporting them to live at home in their communities. It is recognised that the housing sector is already doing a lot to support people living with dementia to stay at home. However, it is also recognised that much of this work is not widely known and acknowledged by partners and customers. The framework offers the sector an opportunity to bring their activities together, demonstrate their contribution and help health and social care partnerships better understand and collaborate with the housing sector. The framework is focused on recording and building on what is already being done.



# The housing and dementia outcomes and commitments

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## The outcomes

There are five housing and dementia outcomes, they reflect what people living with dementia and their carers would like to be experiencing.

- |   |                                                                                                         |
|---|---------------------------------------------------------------------------------------------------------|
| 1 | I receive valuable housing advice when I need it.                                                       |
| 2 | My home has been adapted or designed to suit me and support me to stay at home.                         |
| 3 | I feel listened to and involved in decisions that matter to me.                                         |
| 4 | I know about housing choices and feel able to plan for my future.                                       |
| 5 | I am supported to live safely and independently at home and to participate in the life of my community. |

## The commitments

Organisations agreeing to support people living with dementia to achieve the outcomes are invited to sign up to the following commitments, which are aligned with the key themes in the Scottish Government's Age, Home and Community strategy: right advice, right home and right support.



### Right advice

- a To signpost people who may need support to relevant advice agencies.
- b To understand people living with dementia and their families and carers.
- c To raise awareness and provide training to staff and communities.
- d To develop local information and housing advice to support people living with dementia, drawing on the guidance available ([DEEP Guides](#)).



### Right home

- a To develop a housing health check which could become part of the post-diagnostic support package.
- b To be able to provide and access a range of adaptations which support people living with dementia to stay at home.
- c To support access to technology and technology enabled care.
- d To incorporate dementia friendly design principles into improvement, maintenance and new build specifications.

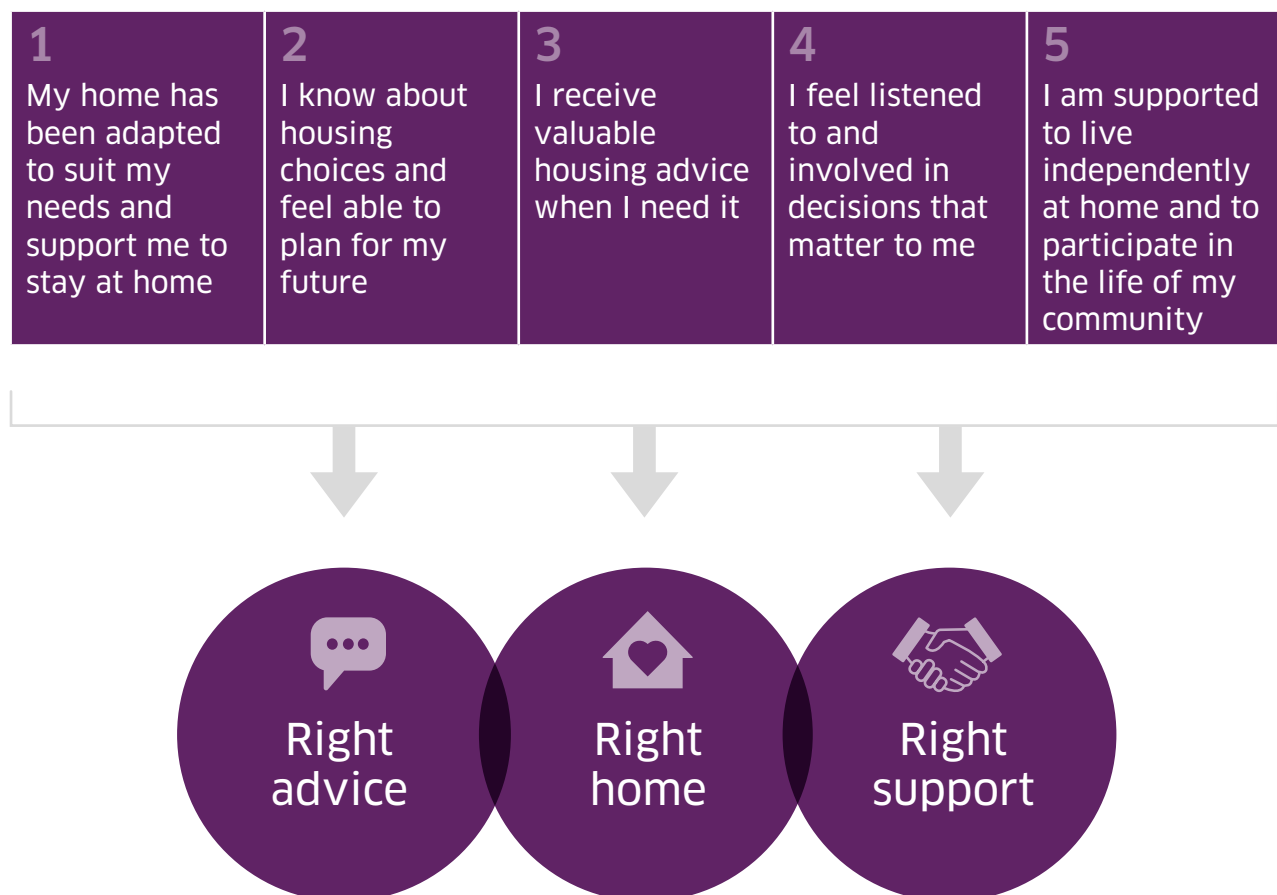


### Right support

- a To ensure that policies and processes are dementia friendly.
- b To work with partners to provide services to support people living with dementia to stay at home or return home quickly.
- c To contribute to creating dementia friendly communities.

## The self-assessment framework

The framework has been designed around the five outcomes and the supporting commitments which are structured to support the key themes in Scottish Government's Age, Home and Community strategy. It includes examples of the things which organisations could do and should consider in order to support the delivery of the outcomes and to meet the commitments.





The template offers examples of some of the things which organisations should consider as part of reviewing how they design and deliver their services, it is not a definitive list. Organisations should use the template to review what they currently do and identify areas for improvement which should then become part of their action/improvement plan.

Organisations can set themselves specific in-year targets of what they can realistically achieve as part of working towards supporting the outcomes and meeting the commitments.

## Blank housing and dementia self-assessment template

Copies of the template will be available for download from CIH Scotland's website: [www.cih.org/scotland/dementiaframework](http://www.cih.org/scotland/dementiaframework). See the following guidance on sources of evidence for meeting the commitments.

Housing and dementia self-assessment			
Right advice			
Commitment	Linked to outcomes	Evidence/comments	Action/improvement (if required)
a. To signpost people who may need support to relevant advice agencies.	1, 4 and 5		
b. To understand people living with dementia and their families and carers.	3		
c. To raise awareness and provide training to staff and communities.	1, 2, 3, 4 and 5		
d. To develop local information and housing advice to support people living with dementia, drawing on the guidance available (DEEP Guides).	2, 3 and 4		

## Guidance on sources of evidence for meeting the commitments

Right advice		
Commitment	Linked to outcomes	Evidence/comments
To signpost people to relevant advice agencies who may need support.	1, 4 and 5	<p>Housing staff liase regularly with Dementia Link Workers.</p> <p>Housing staff assist and support early diagnosis by liasing with families/primary care.</p>
To understand people living with dementia and their families and carers.	3	<p>Support staff are provided with training on dementia.</p> <p>Staff understand the cultural and language issues for people living with dementia.</p> <p>Training and briefing on dementia is provided for contractors.</p>
To raise awareness and provide training to staff and communities.	1, 2, 3, 4 and 5	<p>Awareness of dementia is raised among the community and among staff.</p> <p>Training on dementia is provided for staff and contractors.</p>
To develop local information and housing advice to support people living with dementia, drawing on the guidance available ( <a href="#">DEEP Guides</a> ).	2, 3 and 4	<p>Local information on dementia is developed and made widely available.</p> <p>Specific housing advice is in place for people living with dementia.</p>

Right home		
Commitment	Linked to outcomes	Evidence/comments
To develop a housing health check which could become part of the post-diagnostic support package.	1, 3, 4, and 5	A housing health check is in place and routinely offered as part of the post-diagnostic support package.  Contractors are briefed on dementia as appropriate.
To be able to provide and access a range of adaptations which support people living with dementia to stay at home.	2 and 5	There is a menu of adaptations and equipment in place for people living with dementia.
To support access to technology and technology enabled care.	2 and 5	Staff are aware of technology enabled care which can provide support to people living with dementia.
To incorporate dementia friendly design principles into improvement, maintenance and new build specifications.	2 and 5	Dementia friendly design principles are incorporated in improvement, maintenance and new build specifications.

Right support		
Commitment	Linked to outcomes	Evidence/comments
To ensure that policies and processes are dementia friendly.	1, 3 and 4	The housing organisation's policies and process are dementia friendly and have been developed with contributions from people living with dementia and their carers.
To work with partners to provide services to support people living with dementia to stay at home or return home quickly.	4 and 5	<p>Joint working in place with partners who provide support for people living with dementia.</p> <p>Housing services are part of the support package available to people living with dementia.</p> <p>Arrangements are in place to assist hospital to home.</p>
To contribute to creating dementia friendly communities.	5	Dementia friendly community design principles are incorporated into new build specifications.





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