

A national conversation on a new Dementia Strategy

Response submitted to the Scottish Government 05 December 2022

This is a response to the Scottish Government's consultation to revise the National Dementia Strategy 2017-2022.

Introduction

We welcome the Scottish Government's review of the national Dementia Strategy. Over 90,000 people in Scotland are living with dementia and this number is expected to increase significantly as our population continues to age. Housing is key to supporting people to live well with dementia and our response to this consultation draws on CIH Scotland research into the role of housing, the work and recommendations of the National Housing and Dementia Forum, and feedback from our members through conversations and an online survey.

Consultation questions

1. What does dementia mean to you and those around you?

Housing is key to achieving the Scottish Government's long-standing commitment to support people to live well at home, or in a homely setting, for as long as possible. The right housing and support can help people to remain part of their community, retain their independence and live well with dementia. Appropriate housing can also help to prevent unplanned admissions to hospital, support discharge from hospital and avoid or delay the need for more costly residential care.

CIH <u>research</u> and the recent work of the <u>National Housing and Dementia Forum</u> (the Forum) highlight the vital services provided by the housing sector but also make recommendations on what more needs to be done.

Revising the national dementia strategy presents an opportunity to ensure that the role of housing is reflected in the strategy and the recommendations of the Forum are implemented. Partnerships between housing, health and social care also need to be strengthened, and placing housing firmly within the new strategy will help to



reinforce the importance of housing in delivering better outcomes for people living with dementia, their families and carers.

2. What supports work well for you?

The housing sector can support people to live well with dementia in a number of ways including:

- Training and awareness raising for staff at all levels.
- Incorporating dementia friendly design elements within new housing developments.
- Delivery of specialist dementia friendly developments and Housing with Care.
- Providing advice, information and funding for aids and adaptations.
- Including information online and in tenant newsletters or signposting to other sources of support.
- Making connections with local and national organisations offering support or social activities for people living with dementia, their families and carers.
- Developing and implementing a dementia strategy specific to the organisation.
- Developing and implementing dementia friendly policies, including the use of dementia friendly language.

The <u>Dementia Pathways practice guidance</u> published by CIH Scotland in 2017 includes examples of the practical steps some social landlords are taking to support people living with dementia. These include:

- Awareness of the early signs of dementia, starting a conversation and signposting to other sources of support.
- Assessing the suitability of homes, providing adaptations and, where appropriate, considering different housing options.
- Creating personalised care packages that can be adapted as needs change.
- Multi-agency approaches to ensure that individuals receive the support they need. This can include partnership between housing organisations, health and social care, and external agencies such as third sector organisations and community groups.

However, these measures are not consistent across housing tenures or across different housing providers. The <u>Housing and Dementia Framework</u> developed by CIH Scotland, Healthcare Improvement Scotland's ihub and Alzheimer Scotland, with input from people with lived experience of dementia, is a self-assessment framework designed to help housing organisations map out existing good practice within their organisation and identify where further actions could be taken. The resources are free to use and voluntary, but we do encourage organisations to 'sign up' to the Framework to show their commitment and create a network for sharing practice.



We will continue to promote this tool to the housing sector. However, feedback from the sector suggests that it can be difficult to find resources for activities that are not statutory. This is always the case, but social landlords are coming under increasing financial pressure caused by inflation, ongoing challenges following the pandemic, and unexpected crisis such as the Ukrainian resettlement project. Clear leadership from the Scottish Government about the importance of housing and dementia would help to focus attention and encourage housing organisations to consider their practice. Additional financial resources to support implementation of dementia friendly practice (such as staff training, dementia friendly developments, aids and adaptations) would also be welcome.

While social landlords are well placed to support people living with dementia if they have the resources to do so, our work with the Forum highlighted that tenants in the private rented sector (PRS) and homeowners can struggle to find the right advice and information, or access the funding needed to make adjustments to their home. This and other challenges are outlined in more detail in the section below.

3. What challenges need to be addressed?

As outlined above, the housing sector can support people to live well with dementia, but to ensure the best housing outcomes for people living across all tenures, some challenges do need to be addressed.

The Forum's report, <u>Living well at home: housing and dementia in Scotland</u>, published earlier this year is based on evidence gathered from a wide range of experts and people with lived experience, and makes recommendations on what further actions are needed to support better housing outcomes for people living with dementia.

We urge the Scottish Government to support the implementation of the recommendations in the full report, <u>available here</u>. A summary of key points from the Forum and CIH Scotland's wider work on housing and dementia are outlined below.

Cross-tenure access to advice, information and support

While the social sector is well placed to support people with dementia, people who are living in the PRS or who own their own home may not know where to find advice and information, and good outcomes often depend on the person's financial circumstances and ability to navigate what can be a complex system.

Housing is a basic human right and more needs to be done to ensure that tenure is not a barrier to accessing the right information, advice and support. Forum recommendations included the development of an online resource where people can easily access information, support for third sector organisations such as



Housing Options Scotland and Care and Repair, and review of the adaptations process and funding. It was also noted that more needs to be done to inform private landlords about their obligations in relation to adaptations.

Meeting housing need

We know that there is a lack of suitable housing options for people at every stage of life, but more needs to be done to understand and meet older people's housing aspirations. The Forum report recommends research be undertaken to better understand housing need and supply for older people.

We welcome the Scottish Government's commitment to revising Housing for Varying Needs - advisory standards for new homes funded through the Affordable Housing Supply Programme (AHSP) - and that this work will help to inform a new standard for all homes being built in Scotland. However, it is not clear at this stage what the new standards will be and to what extent they will be applied in the private sector.

Building homes that are more accessible and can be adapted to meet people's changing needs over time does not disadvantage anyone. All new homes being delivered in Scotland should be built to higher standards of accessibility and adaptability as standard. This should be reflected in AHSP funding. We also encourage the Scottish Government to consider simple dementia friendly design elements as part of the review of Housing for Varying Needs.

Our work has also highlighted the need for more specialist accommodation to support people in later life and this will require more up-front funding and longterm certainty for social landlords. This issue is explored in more detail under the 'partnership working' section below.

Tackling stigma and raising awareness

There is stigma associated with ageing, and often people avoid having conversations about their housing needs. This may be because of a strong emotional attachment to their home, questions of inheritance, or the complexity of coming to terms with a dementia diagnosis meaning that housing is not considered among other priorities.

While we understand that dealing with a dementia diagnosis can be a very difficult time for individuals and families, having an early conversation about housing can help people to start considering their longer term needs and avoid having to move in a crisis. We think that information about housing should form part of postdiagnostic support. The Forum also recommends commissioning a national conversation on housing in later life to normalise conversations about housing and ageing.

CIH Scotland's work on the role of housing in supporting people with dementia has also identified a gap in awareness and understanding of dementia for housing



staff. We recommend at least basic awareness for staff across all roles, and more specialist training for roles where this is required.

Feedback from the sector suggests that while some organisations do already offer training for staff (particularly those specialising in housing for older people), some would require additional resources to commit to a regular programme of training.

Supporting people to move home if they need to

While most people want to stay in their home for as long as possible, it is important that people can make a positive choice to move home if their needs change. The Forum report identified a number of barriers that need to be overcome to prevent people having to move in a crisis. These include negative perceptions of ageing, lack of suitable or desirable housing options, lack of awareness about options, logistics of moving home and fear of losing local connections.

The ability to plan ahead for future housing needs is essential to avoid moving in a crisis which can lead to rapid deterioration in a person's condition and the need for more costly interventions.

Partnership working with Heath and Social Care

While there are positive examples of partnership working between housing, health and social care in many areas, this would be further strengthened by reflecting the role of housing in the new national dementia strategy.

Speciality housing such as the Housing with Care model offer an alternative to care homes by providing additional care to residents as and when it is needed. This allows people to stay within their community for longer and can also free up NHS resources by avoiding unplanned admissions to hospital or facilitating a return from hospital.

The Forum report includes a case study of Varis Court, a Housing with Care development managed by Hanover Housing Association, delivered in partnership with Health and Social Care Moray. The NHS initially leased five flats within the development to be used as Augmented Care Units (ACUs) where people could receive additional care when required. <u>Evaluation</u> demonstrated that this approach showed early signs of positive impact on emergency hospital admission rates and reduced costs associated with hospital admissions. Despite these positive outcomes, the NHS has not extended the contract.

This example shows how high-quality housing can be delivered through partnerships between housing, health and social care. However, too much of the financial risk for developments like this currently sits with the housing provider in terms of up-front capital costs and the longer-term costs if partners are able to withdraw at the end of short-term contracts. We need to see a more equal partnership between health and social care if more specialist accommodation is to be provided to meet the needs of our ageing population.

4. How would addressing these challenges change lives?



Chartered Institute of Housing Scotland

Improving housing outcomes for people living with dementia will help to achieve the Scottish Government's long-standing commitment to support people to live well at home, or within a homely setting, for as long as possible.

First and foremost, supporting people to live well at home is better for individuals and their families. We know that most people want to stay in their own home, or within the community where they have established social networks. However, the right housing and support also provides better value for money by preventing unplanned admissions to hospital and residential care.

5. What do we need to build on/learn from what has been done before?

As outlined above, there are many examples of good practice in the housing sector as well as research and guidance. In fact, the Forum heard that sometimes the issue is not with the availability of information, but in some cases finding the *right* information. As mentioned above, one recommendation is for the Scottish Government to create an online platform bringing together different sources of information in appropriate formats for different audiences. E.g. design guidance for developers, housing information for practitioners, and information for people living with dementia, their families and carers.

In particular, we would draw attention to the following publications as useful sources for learning:

- Living well at home: housing and dementia in Scotland report and recommendations from the National Housing Forum <u>https://www.cih.org/media/ay0mo1x4/living-well-at-home-2.pdf</u>
- Housing and Dementia Framework a self-assessment framework to support better practice in the housing sector https://www.cih.org/media/oqnbtkaj/housing-and-dementia-framework.pdf
- Dementia pathways: housing's role research setting out the role of housing in supporting people to live well with dementia <u>https://www.cih.org/media/3nud335z/dementia-research-findings-complete-final.pdf</u>
- **Dementia pathways**: practitioner guidance practical information and examples for the housing sector <u>https://www.cih.org/media/e5qci4ku/cihdementiapathways-practitioner-guidance-final.pdf</u>
- Evaluation of a new service model evidence and evaluation of Housing with Care development partnership between Health and Social Care Moray and Hanover Housing Association <u>https://ihub.scot/media/6047/moray-evaluation-fnct_april19.pdf</u>
- Being home: housing and dementia in Scotland an overview of policy and



practice in relation to housing and dementia <u>https://www.uws.ac.uk/media/4035/being-home-full-report.pdf</u>

 Care and Repair dementia enablement project – evaluation of a pilot project supporting people with dementia to remain independent at home <u>https://www.lifechangestrust.org.uk/care-and-repair-dementia-enablement-project-</u> <u>evidence-and-learning</u>

What else would you like to tell us?

Living well at home starts with the right housing and support. The essential role of the housing sector should be better reflected through the national dementia strategy and we look forward to working with the Scottish Government and partners to implement the new strategy, ensuring that every person living with dementia in Scotland is able to access the housing and support they need to live well.



About CIH

The Chartered Institute of Housing (CIH) is the independent voice for housing and the home of professional standards. Our goal is simple - to provide housing professionals and their organisations with the advice, support, and knowledge they need to be brilliant. CIH is a registered charity and not-for-profit organisation. This means that the money we make is put back into the organisation and funds the activities we carry out to support the housing sector. We have a diverse membership of people who work in both the public and private sectors, in 20 countries on five continents across the world. Further information is available at: www.cih.org.

Contact:

Ashley Campbell CIHCM Policy and practice manager CIH Scotland <u>ashley.campbell@cih.org</u>

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