



DEMENTIA PATHWAYS HOUSING'S ROLE KEY RESEARCH FINDINGS



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During 2016 CIH Scotland commissioned Arneil Johnston to deliver the second phase of its housing and dementia programme. This phase of the research focused on improving the links between housing organisations and partners in health, social care and the third sector, with a specific emphasis on the role of the housing professional in meeting the needs of those living with dementia.

It is hoped that the outcomes of this study will enable an improved understanding of housing's role in dementia care, by setting out clearly the contribution that housing staff and services can make.

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1.1 Best practice and literature review

The first stage of the research involved compiling evidence of the latest thinking, innovation and practice on housing and dementia issues. Working in partnership with the University of Stirling the literature review focused on issues of public policy, empowerment and choice, design, service delivery arrangements, technology and partnerships. It also examined best practice examples and the implications for frontline housing delivery. Key learning outcomes were:

1. To encourage proactive policy and practice responses, there's a need for better awareness of the growing impact of dementia as an issue for society, community and public services. More specifically, there's a need for training across frontline housing professionals on dementia as a condition, related behaviours and good practice models (such as Alzheimer Scotland's 8 Pillars Model of integrated dementia care).
2. There's a well-developed national policy framework for dementia which is closely aligned to the integration of health and social care services. Housing's contribution to the strategy is acknowledged and focuses on a broad goal of enabling people to live independently at home and in the community. However, the role of housing in enabling independence could be more widely recognised and promoted.
3. Best practice concepts that should influence housing policy and practice as it relates to meeting the needs of people affected by dementia include the following:
 - a. Promote practice which encourages people affected by dementia to be actively involved in decision-making, for example co-production and housing options approaches.
 - b. Implement dementia-friendly design principles in adapting the home environment of a person affected by dementia to promote independence, wellbeing and safety.
 - c. Dementia care models (such as Alzheimer Scotland's 5 and 8 Pillars Models) should integrate housing contribution and interventions into wider health, care and support interventions. For details of the Pillars Models see http://www.alzscot.org/campaigning/five_pillars and http://www.alzscot.org/campaigning/eight_pillars_model_of_community_support
 - d. The benefits of integrating technology into the home environment of a person affected by dementia need to be mainstreamed and not focused on specialist housing provision.
 - e. The importance of partnership and joint working in meeting the needs of people affected by dementia is crucial. The extent to which housing providers are acknowledged as core partners should be enhanced.
4. There's a need to acknowledge and build appropriate service delivery options to meet the needs of the majority of people affected by dementia who are homeowners, including housing interventions such as adaptations, repairs and support to maintain independent living.
5. Alternatives to care home provision, such as specialist dementia care settings or housing projects are less developed in Scotland than in the UK and Europe. Ensuring a diversity of housing options is available to meet the needs of people affected by dementia should be considered within the context of the National Dementia Strategy.

1.2 Housing's role in the dementia journey

The research mapped out the role of housing staff and services across four key interactions (pathways), which form important stages of the dementia journey.



Pathway 1 – Assisting and supporting early diagnosis

The role of a housing worker is to recognise where changes in normal patterns of behaviour could be dementia-related and to signpost customers to services that can improve wellbeing and encourage diagnosis. The housing role is NOT to spot or diagnose dementia.



Housing's role in assisting and supporting early diagnosis is:

- to recognise where persistent or notable changes in a person's normal pattern of behaviour could be dementia-related;
- to ask simple questions which enable the assessment of a person's ability to live safely and independently where signals of (dementia-related) changes in behaviour are present;
- to share information on the benefits of regular engagement with health services in promoting wellbeing and signpost customers into services that maintain independent living;
- where appropriate, to support dialogue on the benefits of early dementia diagnosis with housing customers, support workers, carers or families;
- where appropriate, to encourage a person to take action to seek diagnosis through active signposting into the dementia diagnosis pathway;
- to encourage early consideration of housing interventions in post-diagnosis support planning processes, promoting a housing options approach to future planning; and
- to use Housing Contribution Statements to encourage early housing involvement in post-diagnostic support processes and pathways.



Practice Exchange

A **South Lanarkshire Council** sheltered housing officer completed a support needs assessment with Mrs Y and her daughter. The housing officer noticed signs of dementia (for example, Mrs Y was repeating parts of the discussion, and looking to her daughter for prompts/answers) and discussed these symptoms with Mrs Y's daughter as part of the assessment. Following the assessment, Mrs Y's daughter was given advice on support services and medical pathways in relation to dementia. Mrs Y was subsequently housed in a sheltered housing development with access to day care services, social activities and health care services which have had a positive impact on her general wellbeing. With these interventions, it has been possible for Mrs Y to avoid a residential care setting.



Pathway 2 - Early assessment of the suitability of someone's home

Housing workers should understand the importance of environment in meeting the needs of people affected by dementia and the impact of design interventions in supporting independence so that they can contribute to housing suitability assessments and manage the process for commissioning, funding and delivering adaptations.



Housing's role in the early assessment of the suitability of someone's home is:

- to understand basic dementia-friendly design principles and how these features help daily living for a person affected by dementia;
- to commission and participate in housing suitability appraisals in collaboration with occupational therapists and design professionals, encouraging early consideration of housing issues;
- in delivering housing suitability appraisals, to ensure that adaptations to the home environment are both person-centred and dwelling-appropriate;
- to manage the process for funding and delivering property adaptations following a housing suitability appraisal;
- to promote the engagement and involvement of people affected by dementia in adapting the home environment, encouraging co-production of decision-making;
- to provide information to the wider community on the range of dementia-related housing interventions that can support wellbeing and independent living;
- to reflect on the environments in which housing professionals support or work with people affected by dementia and identify the potential for simple improvements/changes; and
- to ensure that housing asset management and development strategies incorporate dementia-friendly design principles as part of a preventative approach to housing investment.



Practice Exchange

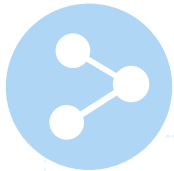
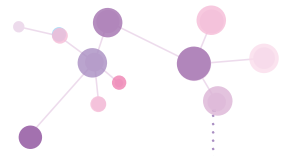
Viewpoint Housing Association has developed an environmental audit pro forma which is completed by staff. The audit is based around recent good practice in dementia design and picks up issues such as lighting, colour, contrast and signage. The assessment is used to identify areas of improvement which can be incorporated into cyclical and capital investments.



Practice Exchange (continued)

Examples of assessment criteria within the audit include:

- The entrance to the unit is welcoming, clean and well-lit. Consider if there is an institutionalised appearance? Is it freshly decorated?
- There is a contrast in colour between the signs and background mounts.
- Taps are traditional in appearance, for example crosshead and are simple to operate, with clear indications of hot and cold water.
- Curtains are of a plain pattern and contrast with the colour of adjacent walls.



Pathway 3 - Enabling a person affected by dementia to remain at or return home quickly

Housing workers should understand the key housing interventions that can support people affected by dementia to live independently so that they can work with partners to deliver positive housing outcomes. Housing workers should play a supporting role in enabling effective admission and discharge processes.



Housing's role in enabling a person affected by dementia to remain at or return home quickly is:

- to play a positive and supportive role in an integrated approach to dementia care by ensuring that the full range of housing interventions to support independent living are considered and made available;
- to interact with occupational therapists, carers and the family of people affected by dementia to understand the impact of dementia on day-to-day living, identifying housing interventions to support independent living;
- to recognise the potential of assistive technology to enhance or complement adaptations to the home environment of a person affected by dementia;
- to encourage the development of processes and systems that enable a strong housing response within a collaborative approach to dementia care, for example multi-agency protocols, named contacts, joint training;
- to recognise the range of resources and technological developments that can be used to support independent living, including options delivered through social work services and other resources;
- to deliver a robust approach to tenancy management should an emergency or unplanned admission take place, protecting the housing status of a person affected by dementia;
- to support hospital discharge planning through involvement in housing suitability appraisals, assessing options for adaptations, technology, housing support or specialist accommodation;



- to promote and encourage a housing options approach to discharge planning, including the involvement of the people affected by dementia; and
- to encourage engagement and participation in community activities to prevent social isolation for those living with dementia as part of a reablement approach to dementia care.



Practice Exchange

Following an assessment of the suitability of Mr B's home, **Castle Rock Edinvar** housing association took the decision to make adaptations to the property to allow Mr B to remain at home safely. A number of changes were made, including:

- sensors installed so that lights came on when Mr B approached them;
- the property repainted internally to enhance the amount of light;
- grab rails installed in the bathroom, in a contrasting colour to the walls for easy visibility; and
- the entrance mat changed to the same colour as the rest of the floor coverings so that it wasn't perceived as a barrier by Mr B, causing him to remain indoors.

Castle Rock Edinvar is now planning to add dementia-friendly design features into investment budgets, in an attempt to future-proof assets to support people living with dementia.



Pathway 4 - Ensuring holistic consideration of assistance and support as dementia progresses

Housing workers should understand the boundaries of their role in meeting the needs of people affected by dementia and build positive working relationships with partners to support people affected by dementia. To do this, housing organisations should offer training, develop policies, and promote dementia awareness.



Housing's role in ensuring holistic consideration of assistance and support as dementia progresses is:

- to ensure basic dementia awareness and an understanding of the role of housing staff and services in meeting the needs of people affected by dementia is achieved at all levels within housing organisations;
- to assess the training needs of housing staff and develop dementia training programmes tailored to technical, estate management, support, regeneration and customer care roles;
- to develop dementia-specific customer care standards;



- to develop and implement effective organisational strategy and policies ensuring that housing support and intervention is part of an integrated approach to dementia care;
- to proactively engage with and build positive working relationships with partners involved in the delivery of integrated dementia care, including health, social work and dementia services;
- to promote the role of housing options within an integrated approach to dementia care that is comprehensive, and to provide person-centred information and advice to achieve positive housing outcomes;
- to improve awareness of the 5 Pillars Model of post diagnostic support and 8 Pillars Model of community support and housing's role in supporting an integrated approach to dementia care; and
- to assemble and share good practice of housing's role in meeting the needs of people affected by dementia across the housing sector and dementia partners.



Practice Exchange

Abbeyfield Scotland Ltd has been bringing external local agencies and charity groups into a housing context in order to deliver a range of projects, including:

- dementia-friendly cafes;
- musical groups;
- men's football;
- Alzheimer Scotland Group; and
- meal service – bringing in outside dieticians to assist with menu planning and specific requirements.

1.3 Testing the requirements for skills and knowledge

Frontline housing staff from across Scotland scrutinised the proposed housing role for each dementia pathway, assessing the extent to which staff need to be equipped with the relevant knowledge and skills to perform each role. In every case, the outcomes of validation process provided assurance that the proposed pathway roles for housing in dementia care are relevant and credible in the context of housing policy and practice in Scotland.

The study then returned to the outcomes of the pathway mapping workshops to define the key knowledge and skill requirements associated with each stage in the dementia journey and to define the potential contributions for each staffing group.



In each pathway, what is the role, knowledge requirements and skills for:

Generic frontline staff, including:	Specialist frontline housing staff, including:	Leaders and managers, including:	Policy and strategy staff, including:
<ul style="list-style-type: none"> • housing officers; • housing assistants; • maintenance officers; and • housing advice workers. 	<ul style="list-style-type: none"> • sheltered housing officers or wardens; • housing support workers; and • Care and Repair staff. 	<ul style="list-style-type: none"> • housing managers; • heads of (housing) service; • directors; and • board/elected members. 	<ul style="list-style-type: none"> • housing policy officers; and • commissioning officers.

This aspect of the research programme was central to identifying and assessing whether the housing workforce in Scotland has sufficient understanding and competency in dementia-related issues to play a stronger role in dementia care. Key outcomes of this process include:

1. The only element of the role profile which was consistently questioned by housing staff related to Pathway 1 and the requirement to “share information on the benefits of regular health screening”. This reflects general uncertainty by housing staff on the professional boundaries of housing workers in signposting to health or clinical services. Development work between housing and health sectors on the role of the housing worker in signposting customers into preventative health services could usefully be placed on the agenda of integrated joint boards.
2. While all functional housing staff have a role to play in each dementia pathway, operational staff led the way in Pathways 1 to 3, with managers and strategy staff leading in Pathway 4. These outcomes demonstrate the importance of ensuring that dementia awareness, training and skills development is prioritised across every aspect of a housing service to enable both frontline and support staff to play.

1.4 Knowledge and skills survey

Testing dementia knowledge and workforce competence across housing in Scotland is a key aspect of assessing the capacity of the sector to play a proactive role within an integrated approach to dementia care. It also provides valuable intelligence of the extent and nature of training requirements across the profession. As part of the research, 385 housing workers completed an online survey testing confidence levels in the key knowledge and skill requirements identified as essential in delivering each pathway role.

Survey outcomes give insight into the extent of day-to-day interaction with people affected by dementia across the housing sector, as well as the extent to which housing staff have accessed formal training on dementia issues.



The survey also delivered a clear insight into the readiness of the housing sector to play a proactive role within an integrated approach to dementia care. Some of the key results include:

- Overall, core knowledge requirements across dementia pathways are under-developed in Scotland, with almost one in two staff (46%) stating they have little or no confidence levels in the required knowledge for each pathway. Crucially, 55% of frontline housing staff say they have little of the knowledge required.
- Priorities for developing housing and dementia knowledge generally focus on the housing role in adapting the home environment of a person affected by dementia to encourage independent living, including the use of adaptations and assistive technology.
- Priorities for developing housing and dementia skills generally focus on improved planning, both at a strategic level and at an individual support level. Gaps identified by the survey were the inability to engage with housing suitability assessments or hospital discharge processes.
- Skills development would be beneficial across the housing sector in Scotland and across all dementia pathways given that 30-40% of housing staff state they have little or no confidence levels in required competencies for each pathway. Crucially, 54% of frontline housing staff say they have few of the skills required.
- Key areas for skills development include promoting the role for housing in diagnostic support planning and more generally, in an integrated approach to dementia care.
- Increasing awareness of both the 5 and 8 Pillars Models of dementia care and other dementia policy and practice frameworks for housing must be a priority in the future.

Despite notable gaps in both the knowledge and skills required to make a positive contribution to each dementia pathway, survey outcomes suggest that the housing workforce in Scotland recognises the importance and impact of housing staff and services in dementia care.

Attitudes to dementia

78%

"I agree that housing workers have an important role to play in relation to people affected by dementia"

81%

"I think housing workers have a role in recognising changes in normal patterns of behaviour and signposting to services that improve wellbeing"

64%

"I think housing workers have a key role in the early assessment of the suitability of someone's home following dementia diagnosis"

70%

"I think housing has an important role to play in ensuring holistic consideration of all aspects of assistance and support as dementia proceeds"

3%

"**I do not think** that housing has a key role to play in relation to people affected by dementia"



1.5 Housing and dementia conferences



In November 2016, two housing and dementia conferences were held to identify and share best practice in housing and dementia care and to examine the role of housing providers in promoting greater awareness and acceptance of dementia. These conferences were a key aspect of finalising the research programme and were aimed at frontline housing professionals. Key findings from conference engagement activity include:

- One in four conference delegates defined their key strength in meeting the needs of people affected by dementia as “playing a positive and supportive role in an integrated approach to dementia care”.
- Other ‘strengths’ related to the housing sector’s unique opportunity to spot early signs that a dementia diagnosis may be needed, due to the degree of interaction between frontline housing staff, tenants and other service users.
- Only 3% of conference participants could offer a positive example of a housing options approach to dementia-related information and advice. The core principles of the housing options model could be applied very successfully to meet the needs of people affected by dementia and this is an area of practice which should be prioritised from a learning and development perspective.
- Best practice exchange analysis suggests that housing and dementia practice in the sector is likely to focus on (i) dementia-friendly housing design, and (ii) supporting people affected by dementia to live independently.
- Conference delegates agreed that the issue of dementia should be a greater priority for housing providers across Scotland.
- Delegates agreed that becoming more dementia-friendly would change business and customer outcomes delivered by housing providers with key benefits relating to preventative savings, greater partnership and collaboration, and better awareness and acceptance of dementia issues.



Promoting dementia-friendly communities

Benefits for housing providers:

1. **Preventative benefits** – Tenancy sustainment outcomes could be enhanced if people affected by dementia are able to live safely at home for longer.
2. **Social benefits** – Community cohesion could be enhanced as better acceptance of dementia as an issue is promoted, including the importance of encouraging positive interaction with people affected by dementia as part of an integrated approach to dementia care.
3. **Strategic benefits** – The delivery of dementia-friendly communities should help develop an evidence base of improved outcomes which would help justify and promote future investment in preventative dementia activity.
4. **Attitudinal benefits** – The promotion of dementia-friendly communities would assist in addressing issues of low tolerance to dementia. Housing providers have the potential to improve community awareness and to “break down the stigma” associated with the condition.



1.6 Recommendations

Drawing on all of the research findings a number of recommendations have been developed, aimed at the stakeholders who will be instrumental in promoting and developing the housing role in dementia care.

To promote and develop the housing sector role in dementia care, the **Scottish Government** should:

- promote the role of the housing professional in delivering preventative solutions to people affected by dementia which encourage early action; improve housing suitability; support effective admission, discharge and resettlement; and enable independent living;
- offer guidance on integrating proven dementia-friendly housing design principles into housing investment programmes; and
- identify appropriate service delivery options which deliver housing interventions to the majority of people affected by dementia who don't live in social housing but are homeowners or rent privately, including the timely provision of adaptations, repairs and support to maintain independent living.

Additionally, the National Dementia Strategy (and Housing Investment Programme) should offer mechanisms to fund and test specialist dementia care settings or housing projects to ensure a diversity of housing options is available to meet the needs of people affected by dementia.

To promote and develop the housing sector role in dementia care, **local authorities** should:

- recognise and promote the role of the housing professional in delivering preventative solutions to people affected by dementia which encourage early action; improve housing suitability; support effective admission, discharge and resettlement; and enable independent living;
- encourage and pursue the consideration of dementia as an issue within the 'supporting independence' aspect of the Local Housing Strategy;
- ensure that dementia awareness, training and skills development is prioritised across every aspect of housing services, for example through Scottish Social Services Council (SSSC) Promoting Excellence resources;
- promote the use of the housing options model to deliver positive outcomes for people affected by dementia, ensuring staff are fully trained and confident in its use;
- develop planning and design guidance that supports dementia-friendly adaptations in the wider housing environment and in new-build private sector housing (see HAPPI guidance and Dementia Services Development Centre publications);
- develop a process and protocol for sharing information about people affected by dementia across public services and the third and voluntary sectors involved in dementia care; and
- engage in development work between housing and health sectors on the role of the housing worker in signposting customers into preventative health services.



To promote and develop the housing sector role in dementia care, **housing providers** should:

- recognise and promote the role of the housing professional in delivering preventative solutions to people affected by dementia which encourage early action; improve housing suitability; support effective admission, discharge and resettlement; and enable independent living;
- ensure that dementia awareness, training and skills development is prioritised across every aspect of housing services, for example through SSSC Promoting Excellence resources;
- promote a major expansion of knowledge levels associated with assessing the suitability of the home environment of a person affected by dementia;
- improve awareness of dementia practice, particularly in relation to Alzheimer Scotland's 5 and 8 Pillars Models of dementia care;
- develop and make widely available a statement which outlines the services and assistance provided to support people affected by dementia to live independently and well;
- integrate proven dementia-friendly design principles within asset management strategies and policies for delivering aids and adaptations;
- work towards attaining dementia-friendly status, acknowledging the benefits arising from preventative savings, greater partnership and collaboration, and better awareness and acceptance of dementia; and
- seek a proactive and positive role within health and social care partnerships to promote the preventative benefits of early and ongoing housing design and support interventions for people affected by dementia.

To promote and develop the housing sector role in dementia care, **health and social care partnerships** should:

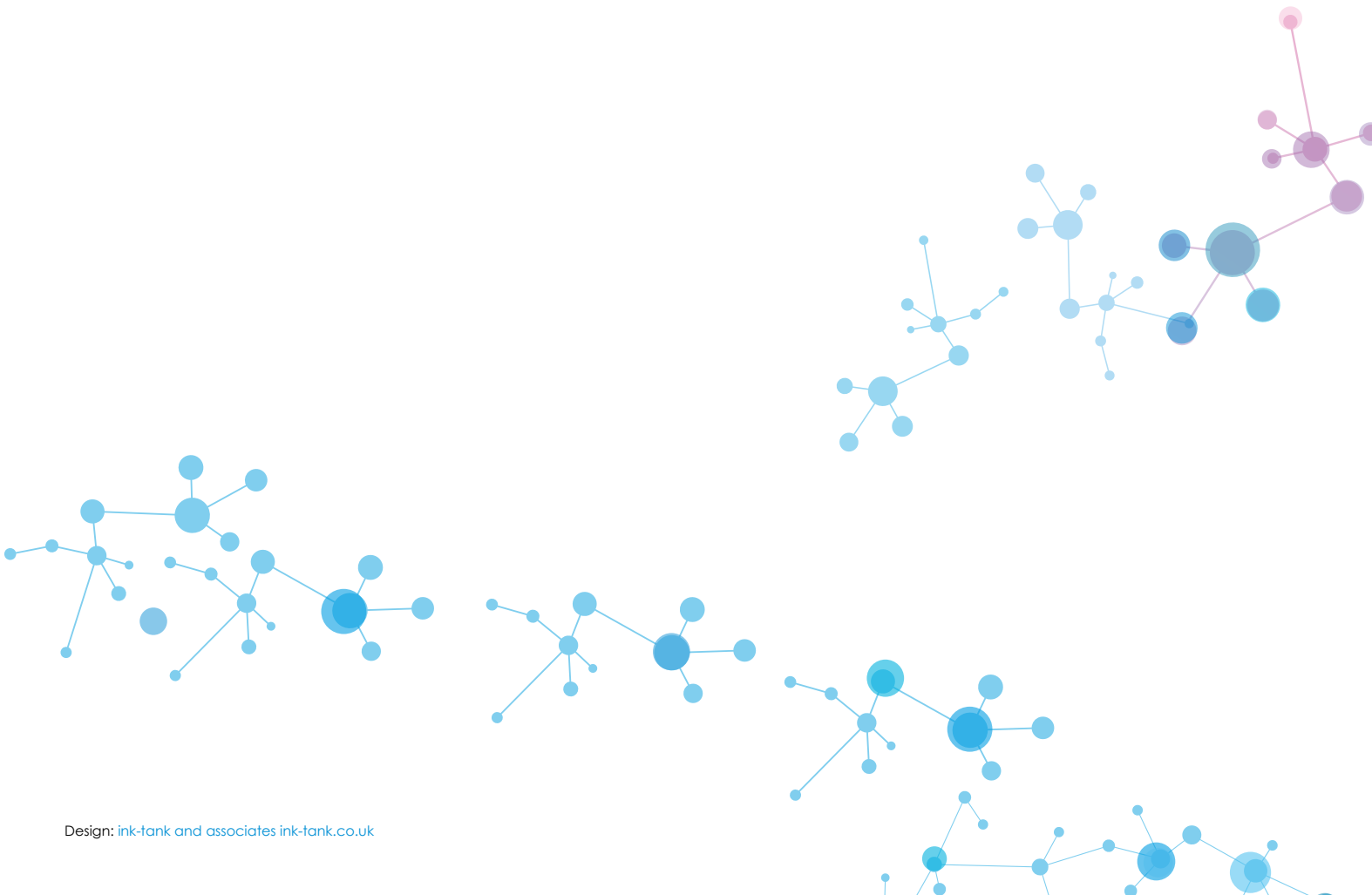
- recognise and promote the role of the housing professional in delivering preventative solutions to people affected by dementia which encourage early action; improve housing suitability; support effective admission, discharge and resettlement; and enable independent living;
- consider how the housing role within the dementia care framework can be developed beyond property and environmental issues to active engagement in supporting independent living; enabling effective admission, discharge and resettlement; and encouraging community participation;
- identify appropriate service delivery options which deliver housing interventions to people affected by dementia who are homeowners or private renters, including adaptations, repairs and support to maintain independent living;
- develop a process and protocol for sharing information about people affected by dementia across public services and the third and voluntary sectors involved in dementia care;
- strengthen interactions and relationships between housing and the range of relevant health and non-statutory support services involved in dementia care; and
- engage in development work between housing and health sectors on the role of the housing worker in signposting customers into preventative health services.

To promote and develop the housing sector role in dementia care, **CIH Scotland** should:

- recognise and promote the role of the housing professional in delivering preventative solutions to people affected by dementia which encourage early action; improve housing suitability; support effective admission, discharge and resettlement; and enable independent living;
- raise awareness of dementia and improve knowledge of dementia practice (including Alzheimer Scotland's 5 and 8 Pillars Models of dementia care) across the housing sector in Scotland;
- work with learning and development professionals to prioritise dementia as a knowledge and skills issue for the housing sector;
- continue to work with the SSSC to support the take up of Promoting Excellence resources in the housing sector;
- encourage practice exchange and inter-sector networking, building on the bank of housing and dementia practice examples identified during this dementia pathways research; and
- recognise and promote the role of the housing professional in delivering preventative solutions to people affected by dementia through training and awareness raising with private sector landlords and letting agents.

Further information on the housing and dementia pathways research, including a housing practitioner's guide can be found on www.cih.org/scotland







 Arneil Johnston

