Scotland

DEMENTIA PATHWAYS
HOUSING'S ROLE
PRACTICE GUIDE

Dementia Pathways Housing's Role Practice Guide

Foreword

This practice guide is important for everyone working with people living with dementia.

Where we live and call home matters hugely to our health and wellbeing. A settled home is critical to our sense of self and wellbeing and provides a foundation from which people can flourish. The activities of housing organisations influence people's everyday lives and the places they live. The homes we build and the services we provide contribute to delivering national health and wellbeing outcomes as well as wider ambitions to create a fairer, healthier and wealthier Scotland.

This is equally - if not more - true for people living with dementia. We have a responsibility to learn from this practice guide and challenge and question whether existing policies and procedures, and staff awareness and skills are as good as they can be. Defining the housing role across the four dementia pathways should not only improve housing sector practice, but can help promote housing-led interventions in an integrated approach to care planning and delivery. It should also encourage acceptance of the preventative benefits of housing interventions amongst our partners in the health and social care sectors in Scotland.

Let's help more people with dementia live independently and well at home.

Amanda Britain
Chair, CIH Scotland
October 2017

Acknowledgements

This practice guide is one of the outputs from a larger research study on housing's role in dementia care carried out for CIH Scotland during 2016 by consultants Arneil Johnston, led by Donna Milton. The guide was produced by Arneil Johnston as part of their work on the study. It is the second study on housing and dementia managed by CIH Scotland and funded by a grant from the previous Joint Improvement Team (JIT).

The project steering group for the research comprised:

- Margaret Moore, Housing Consultant with the Place, Home and Housing team, ihub
- Lyn Jardine, Lyn Jardine Consulting
- Marian Reid, CIH Scotland
- Donna Milton, Arneil Johnston

Particular thanks go to all of the individuals and organisations, in health, social care and housing, who gave their time and expertise to the research. Their interest in the research, and their contribution, has undoubtedly resulted in a richer and more comprehensive piece of work.

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Contents

Dementia Pathways Housing's Role Practice Guide

1. Introduction

CIH Scotland commissioned Arneil Johnston, in May 2016, to undertake research for the second phase of its housing and dementia programme.[1] A summary of the key findings from the research was launched in March 2017.[2] A full report setting out detailed information from the research is available online.[3]

This practice guide contains the main findings and learning from the phase 2 research, which focused on the role of housing practitioners and of housing practice within an integrated approach to dementia care. The housing role was mapped across four housing and dementia pathways that represent important stages of the dementia journey. The pathways were identified by professionals working across housing, health, social care and dementia services. They provide the main structure for the guide.

This guide is aimed at housing practitioners, both frontline staff and managers. It includes:

- recommended guidance on delivering the housing role in practice for each pathway;
- advice on how to maximise the contribution of frontline housing staff in supporting early diagnosis; and
- emerging models of practice and reference materials that may help frontline housing practitioners meet the needs of people affected by dementia.

Aims of the phase 2 research

The overall aim of the phase 2 study was to improve the links between housing organisations and partners in health, social care and the third sector. Six study aims were defined:

1. To analyse and define the links, relationships, processes and practice required to/from housing organisations when supporting people affected by dementia in each pathway and to define the role of housing practitioners in each.
2. To identify the skills and competencies required by housing staff to support the delivery of the housing role in each dementia pathway.
3. To identify the extent to which workforce skills and competencies are currently present or being developed to support the delivery of the housing role in each dementia pathway.
4. To identify emerging practice which highlights the importance of a cultural understanding of dementia within housing organisations, including the involvement of housing staff in delivering support post-diagnosis.
5. To identify emerging practice which highlights how housing organisations, in their role as community anchors, can engage individuals and communities to improve wider understanding and acceptance of dementia.
6. To scope and provide detailed recommendations on the role of housing staff and services in meeting the needs of people affected by dementia.

[1] Phase 1 of the programme focused on the housing sector's engagement in dementia care and publication of design guide *Improving the design of housing to assist people with dementia,* DSDC, CIH, JIT (2013): http://bit.ly/2vwLsk2

[2] *Dementia Pathways – Housing's Role: Key Research Findings,* CIH (2017): http://bit.ly/2ndmNw4

[3] *Housing and Dementia Programme Phase 2: Final report*, CIH (2017): http://bit.ly/2wYlMfl

Research approach

The research approach was interactive. It drew on the expertise of staff across the housing sector in Scotland, and particularly the input of frontline staff, to inform and validate the study's findings and recommendations. The study methodology included:

Literature review – this drew on academic and wider policy literature from the UK and Europe. It brought together the latest thinking, innovation and positive practice in meeting the needs of people affected by dementia. A copy of the literature review and related references is included within the full research report.[4]

Pathway mapping – a series of four multi-agency workshops brought together a range of practitioners from housing, health, social care and dementia services. The workshops included an examination of the role of the housing professional; key interactions, processes and pathways; and information and skills requirements.

The validation and scrutiny process – four engagement sessions were held with housing professionals across Scotland to test and validate the proposed dementia pathway roles.

Skills survey – a Scotland-wide survey of housing professionals was undertaken via CIH's networks. A total of 385 responses were received: 42% were frontline (general), 26% were frontline (specialist) and 19% were managers. Other staff including policy officers made up the remainder.

Engagement events – two conferences were held to explore the role of the housing provider in greater detail and to share practice examples. These events were aimed at frontline staff.

Literature review	Pathway mapping events (x4)	Regional workshops (x4)	Skills survey	Engagement events (x2)
Develop solid evidence base Identify innovation Identify best practice	Define housing staff role over four pathways Validated by health and social care	Frontline housing staff review Role profiles Knowledge and skills requirements	Scotland-wide survey 385 responses Measured extent to which housing staff have dementia skills and knowledge	Identify and share best practice Examine role of housing staff in promoting greater awareness of dementia

[4] *Housing and Dementia Programme Phase 2: Final report, Appendix 2.1: Best Practice and Literature Review*, CIH (2017): http://bit.ly/2wYlMfl

Practice guide structure

Chapter 2 summarises the current context and highlights the 5 and 8 Pillars Models.

Chapters 3 to 6 cover the housing practitioner's role in meeting the needs of people affected by dementia. This role is broken down into the four separate pathways which form key stages in a typical dementia journey. These pathways were predefined by CIH Scotland at the outset of the research and include:

- Pathway 1: Assisting and supporting early diagnosis (Chapter 3);
- Pathway 2: Early assessment of the suitability of someone's home (Chapter 4);
- Pathway 3: Enabling a person affected by dementia to remain at or return home quickly (Chapter 5); and
- Pathway 4: Ensuring a holistic approach to supporting and assisting people affected by dementia (Chapter 6).

Each chapter follows the same format, considering:

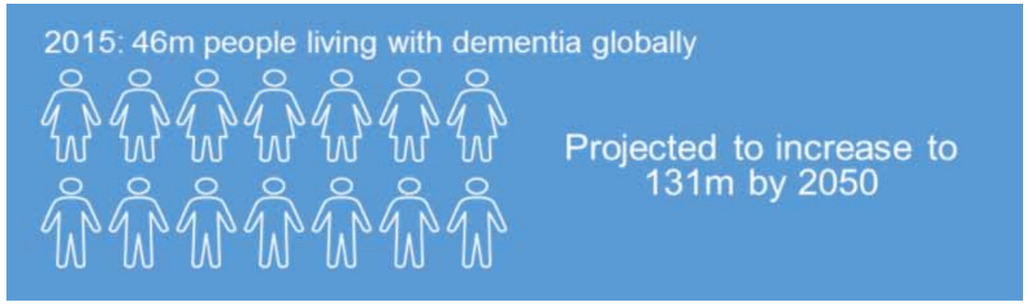
- the housing role within that stage (including being clear about the tasks that housing practitioners would/would not be expected to undertake);
- examples of emerging practice from the sector;
- a checklist of what housing practitioners should know and do for each pathway; and
- recommendations.

Chapter 7 provides a conclusion. The appendix gives some additional resources which may be useful to readers.

2. Dementia care - housing's potential contribution

Dementia as a public policy issue

Dementia is a significant issue, with over 850,000 people estimated to be living with dementia in the UK and over 46 million people living with dementia globally. It is estimated that the global population living with dementia will almost treble (to 131 million) over the next 30 years.[5]



850,000 people affected by dementia in the UK	2/3 are women	2/3 live in the community	670,000 care for someone with dementia	Dementia costs £26bn per annum

Given this increase and the substantial level of public resources dedicated to dementia care, it is essential that housing providers are equipped to make a positive contribution to meeting people's needs.

Scotland's third national dementia strategy was published in June 2017.[6] One of the main priorities for the strategy has been to prevent and shorten hospital admissions and improve services for post-hospital stays. This is consistent with the Scottish Government's housing strategy for older people *Age, Home and Community*[7] and also *Reshaping Care for Older People 2011-2021*[8] where the emphasis is around people staying longer in their own homes and living independently in the community. The strategy notes the importance of adaptations, interventions and housing design, with an acknowledgement of the importance of frontline housing staff.

The planning and delivery framework outlined below ensures that national policy is implemented locally.

- The Public Bodies (Joint Working) (Scotland) Act brings together NHS and council care services in partnership with the housing sector.[9]

[5] *Dementia UK Update, Alzheimer's Society (2014):* http://bit.ly/2guRRFl

[6] *Scotland's National Dementia Strategy 2017-2020 (2017):* http://bit.ly/2vxeolP

[7] *Age, Home and Community:* http://bit.ly/2wVe9Xa

[8] *Reshaping Care for Older People 2011-2021:* http://bit.ly/1U8d9D3

[9] *The Public Bodies (Joint Working) (Scotland) Act:* http://bit.ly/2guFPfo

- National Health and Wellbeing Outcomes: provides a blueprint for the integration model through the creation of Integrated Joint Boards at a locality level.[10]
- Integrated Joint Boards that are required to produce Strategic Commissioning Plans (SCPs) which set out housing activity/contribution to health and social care integration.
- Housing Contribution Statements (HCS)[11] which link to SCPs setting out:
  - key housing issues related to health and social care (mirrored across the SCP and local housing strategies);
  - the shared outcomes and service priorities for housing, health and social care;
  - the current and future housing resource and investment contributing to meeting these outcomes and priorities; and
  - an overview of future challenges and improvements required.

The key point is that the role of housing in dementia care should be recognised within integrated strategic planning.

As part of this research study, practitioners in housing, health and social care services were asked to consider the impact of integration on housing and dementia practice in Scotland. Practitioners concluded that while integration has yet to influence operational housing practice on dementia to any notable degree, there has been some progress in strategy and planning processes given the requirements of HCSs. However, the research found that while the statements have created a focus for housing's contribution to integration planning and improved awareness of housing issues, there remains a lack of understanding about the role of housing organisations across the health and social care sectors generally, and in relation to dementia care specifically.

The housing role in dementia practice tends to be aligned with physical and home environments. For example, the third national dementia strategy acknowledges housing's contribution in helping people affected by dementia to live independently at home, in the community. The role of housing in enabling independence from a wider perspective (including care, support and community participation) could, and should, be more widely acknowledged.

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

Dementia care models: The 5 and 8 Pillars Models

Throughout this practice guide there is reference to the need for better awareness among housing practitioners of models of dementia care and other recommended dementia policy and practice frameworks. In particular, there are repeated references to Alzheimer Scotland's models for:

- the 5 Pillars Model: post diagnostic support; and
- the 8 Pillars Model: integrated dementia care.

[10] *National Health and Wellbeing Outcomes: A framework for improving the planning and delivery of integrated health and social care services:* http://bit.ly/2gpaBmq

[11] *Scotland's National Dementia Strategy 2017-2020 (2017):* http://bit.ly/2vxeolP

What is the 5 Pillars Model of Post Diagnostic Support?

High quality post-diagnostic support, provided over an extended period, is essential to equip people affected by dementia, their families and carers with the tools, connections, resources and plans they need to live as well as possible with dementia and prepare for the future. Alzheimer Scotland's 5 Pillars Model of Post Diagnostic Support shows the key elements that are essential to supporting a person after their diagnosis.[12]

Since 1 April 2013, every person with a new diagnosis of dementia in Scotland is guaranteed a minimum of one year's post-diagnostic support. Its purpose is to provide the security of a named person to work alongside people affected by dementia, their partners and family to ensure they are given the help and support to work through the five pillars. Support focuses on adjusting and managing the likely impact of the illness, both emotionally and practically so they are in the best possible position to manage their symptoms and the practicalities with access to low-level forms of support and signposting until their condition progresses to a point where they begin to need services.

By the end of the year, it is expected that some individuals might require ongoing professional support. However, the purpose of the post-diagnostic support is to enable the individual and their family to develop a robust personal plan, incorporating informal support, maintaining newly developed peer support and developing new community connections to sustain living well and independence for as long as possible.

[12] *Alzheimer Scotland 5 Pillars Model:* http://www.alzscot.org/campaigning/five_pillars

There is no specific role for housing interventions within the 5 Pillars Model. It is hoped that the outcomes of this phase 2 research study, which highlights the importance of early and preventative housing interventions in an integrated approach to dementia care, will encourage recognition of housing's role in post-diagnostic support planning.

What is the 8 Pillars Model of Community Support?

Alzheimer Scotland's 8 Pillars Model of Community Support is a framework for delivering a long term approach to integrated dementia care in a community setting. It can be used as a follow on from the 5 Pillars Model. It can also be implemented sooner for those people who are diagnosed at a later stage with dementia or where the condition progresses rapidly, meaning that the 5 Pillars approach is less suitable.[13] It aims to build the resilience of people affected by dementia and their carers to enable them to live in the community for as long as possible. It also builds on the post-diagnostic support guarantee, to ensure the impact of the investment in early intervention is not lost.

Housing is an essential component under Pillar 7, 'Environment' with the focus on adaptations, aids, design and assistive technology to maintain the independence of those living with dementia and assist their carers.

[13] *Alzheimer Scotland 8 Pillars Model:* http://www.alzscot.org/campaigning/eight_pillars_model_of_community_*support*

The Dementia Practice Coordinator forms the first pillar of community support. This is a named, skilled practitioner operating at the Enhanced Level of the Promoting Excellence Framework.[14] They will ensure access to all pillars of support on an ongoing basis, and will co-ordinate between those delivering care, treatment and support, including linking housing practitioners with occupational therapists, physiotherapy and nursing staff.

The outcomes of the phase 2 study suggest that promoting the benefits of an integrated approach to dementia care and the key role of housing staff and services in enabling independent living must be a priority for the housing sector. There is a need for greater awareness of the role of the Dementia Practice Coordinator within the housing sector, to enable housing practitioners to become more actively involved in dementia care planning and to support delivery.

[14] For more information see Enhanced Level of the Promoting Excellence Framework: http://bit.ly/2wsRtLP

3. Pathway 1: Assisting and supporting early diagnosis

What this pathway covers

This pathway focuses on how frontline staff and managers can assist and enable a person to seek an early diagnosis of dementia. Housing practitioners can make a positive contribution to meeting the needs of people affected by dementia through the provision of information, advice and signposting to services that focus on dementia diagnosis. This may involve participating in support planning to meet the individual's housing and care needs.

Why is early diagnosis important?

Early dementia diagnosis makes a difference to individuals, their families and to the services (including housing providers) that are likely to be involved in providing support post-diagnosis.

Early diagnosis:

- increases the time that people can spend with the people they love, doing the things that matter most to them;
- allows people to access treatments at a time when they can be most impactful and to mobilise support services both for themselves and for their loved ones; and
- enables the individual to have meaningful input to making decisions for care and support in the future.[15]

Pathway 1: Housing's role in assisting and supporting early diagnosis

The day-to-day interactions with tenants and customers associated with tenancy management offer housing practitioners (whether generic or specialist) a unique opportunity to recognise where dementia might be an issue. Through this research, housing staff and partners explored the housing role in assisting and supporting early diagnosis and came to the following conclusion:

> The role of housing staff 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 diagnose dementia.

Housing's role may be summarised as follows:

- 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.

[15] Dementia Services Development Centre: http://bit.ly/2gvPbrx

- 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.

Pathway 1: Practice guidance

During this research study, the nature and extent of the housing role with regards to pathway 1 were explored in detail. The principal issues which emerged focused on the need for frontline staff to:

- recognise the potential signs of dementia;
- know how to have difficult conversations regarding the potential need for diagnosis and build the relationships and trust that enable this type of dialogue;
- understand the early diagnosis pathway and how to signpost people to enter that pathway;
- be aware of local support services for newly diagnosed individuals; and
- know how to support people to be actively involved in decisions regarding their housing, care and support needs post-diagnosis.

These are explored in more detail below.

Stage 1: Triggers, signals or problems that suggest the need for diagnosis

Housing staff should know the signals and symptoms that suggest dementia could be affecting day-to-day living (including mood, behaviour, ability to interact with others and the home environment) and how to spot these signals.

The signals (or triggers) that can be used to detect changes in normal behaviour patterns can be categorised as personal triggers and/or property triggers.

Personal triggers which suggest changes that could be dementia-related include:

- signs of stress, paranoia or anxiety;
- a change in the usual or expected standard of personal care for that person (including clothes, hair and general appearance);
- repeating stories or retelling events or information (sometimes in an inconsistent way);
- social isolation and/or a reduction in social interaction;
- low mood or signs of depression;
- less awareness of personal safety than normal; and
- a change in the way someone interacts with their partner.

Property triggers include:

- more or less interactions with housing services than normal, for example simply being less visible than normal;
- changes in rent payments, particularly when there has been a consistent pattern;
- changes to the normal state of someone's garden or home, for example less tidy, more cluttered;
- an increase in response repairs due to flooding, fires or other hazards that would normally be avoided; and
- frequent instances of the property being obviously insecure, for example leaving the door open.

Dementia, delirium and depression (the 3Ds)

Frontline housing staff should have a basic awareness of the distinguishing characteristics of delirium, dementia and depression, the reason being that delirium, dementia and depression can all manifest with cognitive symptoms which overlap at times. Typical signs and signals are set out below.[16]

A person with dementia may seem:	A person with dementia may also seem to:
apathetic	be forgetful of recent events
less interetested in hobbies or activities	be repetitive in speech or actions
unwilling to try new things	be confused regarding time and place
unable to adapt to change	be neglectful of hygiene or eating
less able to make decisions or plans	become angry or distressed very rapidly
slower to grasp complex ideas	see or hear things that are not there
ready to blame others for 'stealing' mislaid items	
more self-centred	

Stage 2: Checking and confirming a diagnosis may be of benefit

Housing staff should engage in positive conversations to assess if a person can live safely and independently, and understand where and how to direct any concerns, providing the person is comfortable with engaging in a discussion about their experience.

Frontline staff should check whether changes in normal patterns of behaviour form a consistent pattern or have been stimulated by a key life event (for example bereavement).

[16] See also: *http://bit.ly/2eKYP5W* and *http://bit.ly/2goJUy2*

Simple, informal interactions can help build a picture of whether signs and signals could be dementia-related. Positive dialogue can encourage a person to act on changes they have been experiencing.

Staff should keep this dialogue light, informal and ask simple questions about the person's physical health and wellbeing, such as:

- Have you had any recent illnesses?
- Do you have any conditions that affect your day-to-day life?
- Have you been to see your GP lately? If so, what did the GP say?

All interactions should be held at a pace that works for the customer and be carried out with sensitivity.

Practice points to guide communication on dementia diagnosis include:

- discussing options and solutions positively can build trust and customer confidence, while enabling other issues to be shared and identified;
- recognising problems that a person may be facing with day-to-day living should always be in the context of solutions that may be available to address those problems;
- highlighting the benefits of engagement with health and support services is crucial;
- using simple, clear and direct language for example "I think you would benefit from talking to your GP about this"; and
- avoiding the use of the word 'dementia' in these interactions.

Housing staff should note that respecting the person's right to provide information is absolutely paramount. Often, people who are living with the early signs of dementia can be reluctant to engage in dialogue about their symptoms and may develop coping strategies to deal with their impact or avoid conversations on this topic.

Stage 3: Engagement and encouraging diagnosis

Housing staff should know how and when to encourage people to take action with respect to seeking a diagnosis. This would include knowing how to have sensitive conversations about dementia, how to signpost people towards a diagnosis pathway, AND how proactive tenancy management builds trust and enables engagement.

Frontline staff should be aware of the importance of building trust to enable successful conversations on dementia diagnosis to take place. Where possible, individuals themselves should be encouraged and enabled to seek diagnosis. Health and social work colleagues stress that customers should be encouraged to take action on diagnosis themselves.

It is important that staff have basic knowledge of the dementia diagnosis pathway and understand that it starts with GP engagement.

Depending on the nature and extent of interaction with the individual, the potential **pathways to dementia diagnosis** are likely to be as follows:

1. The housing practitioner signposts the individual (with consent) to local support services (such as information and advice services, dementia resource centres, day centres for older people) that can provide practical assistance with dementia diagnosis or further information on dementia.
2. The housing practitioner encourages an individual to make a self-referral to their GP for dementia diagnosis.
3. The housing practitioner makes a referral to social services, with the consent of the individual, to provide assistance in seeking a dementia diagnosis.
4. If consent is withheld, and major concerns are outstanding regarding wellbeing or safety, the housing practitioner should make an urgent adult support and protection referral.[17]

When considering the diagnosis pathway, housing staff should think about whether support or advocacy may be appropriate. Frontline housing staff should not be expected to provide this support or advocacy but instead make referrals to health, care or support agencies, always with the consent of the individual.

Stage 4: Making a referral

Housing staff should know how to communicate and build trust to encourage a person to engage with their GP with a view to seeking a diagnosis. They should also have a good knowledge of alternative support options to encourage diagnosis, the consent to share information process, and of how to assess and act on wellbeing risks.

Frontline housing staff should be clear that their role is to encourage a person to take action themselves in seeking diagnosis and actively signpost them to health services. There is no mechanism for frontline housing staff to make referrals for dementia diagnosis.

Housing staff should be aware that pathway, referral and signposting processes may differ from area to area. Any engagement by a housing practitioner with a third party agency (health, social services or support agencies) on dementia diagnosis must always be supported by the consent of the individual.

If a person resists engaging in dialogue about dementia diagnosis, but outstanding concerns remain regarding the wellbeing or safety of that person, it may be appropriate to engage with carers or family. To assist with this, housing staff should have awareness of the principles of the 'triangle of care',[18] a model that encourages engagement between professionals and their carers. Its use will enable housing staff to ensure that confidentiality and information sharing requirements are not breached in their engagement with carers.

Without disclosing personal information, and where it is possible to do so, housing staff should ask a family member or carer for their views or perceptions of the person and their ability to cope with day-to-day living. If it is not possible to engage with carers or family, and there are significant concerns about the welfare or safety of that individual, housing staff should have confidence to activate an adult protection process through their local authority social work department. Understanding the adult protection process in their area is therefore a key knowledge requirement for frontline housing staff.

[17] Scottish Government priorities for adult protection: http://bit.ly/2iMuuIu

[18] Further reading on the triangle of care: http://bit.ly/2wowX0q; http://bit.ly/2epkbF4; http://bit.ly/1P4W7nm

Stage 5: Managing risk post-diagnosis

Housing practitioners should have a good understanding of what they can and should do following a person's dementia diagnosis. Typically, this could include promoting the role of housing interventions as part of an integrated approach to dementia care.

Housing has a key role to play in the post-diagnostic support process. A working knowledge of Alzheimer Scotland's 5 and 8 Pillars Models provide a basis for this. Housing plays a key role in adapting the home environment and should be involved in planning as needs change. To ensure that person centred housing options are identified and offered, housing staff should be aware of the housing options approach,[19] how it operates in their area and how it can apply to dementia care, so that preventative action can be planned wherever possible.

Pathway 1: Practice exchange

South Lanarkshire Council: spotting when diagnosis may be beneficial and signposting to appropriate services[20]

Mrs A was housebound in an upper floor flat due to complex medical needs and was applying for sheltered housing.

When a sheltered housing officer was undertaking the support needs assessment with Mrs A and her daughter, she noticed that Mrs A was repeating parts of the discussion, and looking to her daughter for prompts to answer and communicate for her. The officer identified these signals as a possible early sign of dementia and discussed it with Mrs A's daughter as part of the assessment. Following the assessment, she provided Mrs A's daughter with advice on support services and medical pathways in relation to dementia diagnosis.

Mrs A was subsequently rehoused in a sheltered housing development with access to day care services, social activities and health care which have had a positive impact on her general wellbeing. The support has enabled Mrs A to continue living in the community and avoid a move to a residential care setting following a dementia diagnosis.

[19] Scottish Government background on housing options approach: http://bit.ly/2ev79cU

[20] For further information and other practice examples: *Housing and Dementia Programme Phase 2: Final report, ...Appendix 7.1: Housing and Dementia Conference Briefing Paper*, CIH (2017): http://bit.ly/2wYlMfl

Pathway 1 Checklist: What housing staff should know and do in assisting and supporting early diagnosis

	What should housing staff know?	What should housing staff do?
Triggers or signals that suggest the need for diagnosis	• How to spot typical personal and property signals that could indicate dementia. • Impact of dementia on memory, learning, reasoning and capacity. • Awareness of resources - DSDC, Alzheimer Scotland, SSSC.	• Signpost to services that promote wellbeing and independent living. • Be assured of the impact of early housing interventions and advice. • Manage sensitive dialogue.
Checking and confirming a diagnosis may be of benefit	• Awareness of signs and symptoms of dementia. • Understand the 3 Ds (dementia, delirium, and depression) and how to avoid confusing them.	• Build a picture of wellbeing through interaction. • Understand person's right to give and/or withhold information. • Know how to assess risk to independent living and where to channel concerns.
Engagement and encouraging diagnosis: what language to use and what to ask	• How to use appropriate language when talking about dementia. • How to signpost to advice, support or advocacy. • How to promote benefits of health screening. • Adult protection pathway.	• Encourage dialogue on wellbeing to build trust. • Use proactive tenancy management to assess ongoing wellbeing. • Signpost to GP services for diagnosis. • Engage with family and carers.
Making a referral	• Encourage the person to engage with GP. • Activate one of four referral pathways based on risk and consent. • Importance of consent to share information.	• With consent, engage with agencies that can support the person. • Record and share objective information that supports housing options work. • Engage with family and carers on potential options.
Managing risk post-diagnosis	• Housing's role in an integrated approach to dementia care. • 5 Pillars Model of post-diagnostic support.	• Promote impact of housing interventions in post diagnostic support. • Encourage early assessment of home environment. • Promote housing options approach to planning.

Pathway 1: Recommendations

Key recommendations for housing practitioners in **assisting and supporting early diagnosis** are as follows:

- Recognise and promote the role of housing in the delivery of preventative solutions for people affected by dementia which encourage:
  - early action;
  - improve housing suitability;
  - support effective admission, discharge and resettlement; and
  - enable independent living.
- Stay up to date with dementia practice, particularly in relation to the 5 and 8 Pillars Models of dementia care.
- Communicate the benefits of early dementia diagnosis to housing customers, support workers, carers and families.
- Encourage customers to take action to seek diagnosis through active signposting to the dementia diagnosis pathways.
- Ensure that dementia awareness, training and skills development is prioritised and delivered across every aspect of housing services to enable frontline, support, managerial and leadership staff to play a proactive role in dementia care, for example through utilising Scottish Social Services Council (SSSC) Promoting Excellence resources[21].
- Promote 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.
- Engage with health colleagues on the role of housing staff in signposting customers to preventative health services.

[21] See SSSC resources on Promoting Excellence in Dementia Care: http://bit.ly/2wsSeo7

4. Pathway 2: Assessing whether the home environment is suitable

What this pathway covers

This pathway focuses on the importance of the home environment for people affected by dementia and the lead role played by housing professionals in commissioning, funding and delivering property-related adaptations. It encourages housing participation in assessment and planning so that a housing options approach may be reflected in housing suitability assessments.

The first phase of the housing and dementia programme included as an output a housing design guide, researched and written by the Dementia Services Development Centre, University of Stirling and published in conjunction with JIT and CIH Scotland. This includes the top 10 housing adaptations and four priority areas which are key knowledge requirements for housing practitioners in the context of pathway 2.[22]

Top 10 housing adaptations

1. Double the usual levels of lighting in the home.
2. Pay attention to acoustics and reduce noise pollution.
3. Ensure there is good signage mounted low enough for older people.
4. Use contrast of tone (rather than colour) to differentiate between walls, skirting boards and floors. Ensure that the tone of flooring/paving is consistent throughout the house and also in outside areas.
5. Use contrast of colour or tone to make switches and objects easily visible.
6. Use objects or pictures rather than colours to differentiate between rooms and different parts of the building.
7. Ensure that kitchen and bathrooms are easy to navigate and interpret. Avoid modern fixtures and fittings such as taps or kettles.
8. Ensure that people can see important rooms, such as the toilet, as easily as possible and that furniture and fittings clearly indicate the purpose of each room. Use unambiguous signage on the doors and in the rooms.
9. Place illuminated clocks in each room indicating whether it is am or pm.
10. All doors should be ideally visible on entering the dwelling. Cupboards should be glass-fronted or open.

Four priority areas

1. Improve lighting.
2. Ensure flooring/paving is consistent in tone.
3. Ensure toilet is easy to find.
4. Ensure good contrast in the toilet/bathroom.

[22] *Improving the design of housing to assist people with dementia,* DSDC, CIH, JIT (2013) http://bit.ly/2vwLsk2

Pathway 2: Housing's role in assessing whether the home environment is suitable

During the phase 2 study, housing staff and partners explored the housing role in supporting early assessment of housing suitability and came to the following conclusion:

> Housing staff should understand the importance of the home 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 may be summarised as follows:

- To understand basic dementia-friendly design principles and how these features help daily living for people 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.
- To deliver housing suitability appraisals, ensure that adaptations to the home environment are both person-centered and dwelling-appropriate.
- 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 physical environments in which housing professionals support or work with people affected by dementia and identify the potential for simple improvements/changes.
- To ensure that housing asset management and development strategies incorporate dementia-friendly design principles as part of a preventative approach to housing investment.

At the frontline staff workshops, which validated the housing role, it was envisaged that operational staff would work in partnership with specialists to carry out housing suitability assessments, managers would take a lead in budget approval and strategy staff would lead in planning and commissioning.

Pathway 2: Practice guidance

During this research study, the nature and extent of the housing role with regards to this pathway were explored in detail. The principal issues which emerged focused on the need for housing practitioners to:

- understand the impact of old age and dementia and why environments matter in dementia care;
- have knowledge of dementia-friendly design principles;
- reflect on the environments in which housing practitioners support or work with people affected by dementia and identify the potential for simple improvements and changes; and
- identify where and how to access more detailed advice on dementia-friendly design.

These are explored in more detail below.

Stage 1: Ensuring housing is integral to housing suitability assessments

Housing staff should be aware of, and able to access, support planning processes for people affected by dementia (for example joint working protocols) so that housing services receive early notice of a diagnosis. This should bring housing staff together with a range of staff involved in providing housing, care and support solutions.

Housing staff will play a supporting role in assessing whether a housing environment is suitable for someone with a dementia diagnosis (and often as part of the hospital discharge procedure). Usually, occupational health specialists will take primary responsibility for undertaking housing suitability assessments, with housing partners overseeing the investment required to make agreed changes (for example, through the delivery of aids and adaptations). Housing staff should understand the importance of ensuring people affected by dementia can remain in their home for as long as possible.

Getting the assessment right: DSDC observations

According to DSDC, housing staff should consider the following principles when supporting the delivery of housing suitability assessments:

- People affected by dementia live in all types of housing that will provide a broad range of challenges to independence as their dementia progresses.
- Early assessment by housing providers is crucial to making pre-emptive changes to ensure wellbeing and independence is maintained and may require support from an occupational health professional. Key areas (such as such as the need for property adaptions, housing design interventions, assistive technology and tenancy sustainment support) should be considered by all concerned with the provision of care and support services.
- Where possible, the assessment should involve the person being assessed.

Should remaining at home not prove to be possible, housing staff should play a key role in advising on potential housing options and alternatives, for example moving to a ground floor accommodation or specialist/sheltered housing.

The principle of personal engagement should be pursued wherever possible with 'choice', 'empowerment' and 'person-centred' being important principles for housing staff. The level of involvement or engagement with people affected by dementia is likely to depend on the stage of dementia and the extent to which the person has capacity to make decisions either by themselves or with appropriate advice. Therefore, housing intervention at the earliest possible stage maximises the opportunity for meaningful choice to be exercised by people affected by dementia.

In situations where the person does not want assistance, or actively refuses support, and housing staff have concerns about the tenant's wellbeing, advice should be sought from a relevant professional, generally a social worker involved in adult protection.

Stage 2: Key elements of a housing suitability assessment

Housing staff should undertake the suitability assessment of a person's home in partnership with experts and other relevant professionals (for example, occupational therapists). The needs and preferences of people affected by dementia and their carers will be key considerations throughout.

All housing staff will benefit from a basic understanding of the design principles that can enhance the living circumstances and wellbeing of people living with dementia.[23] Specialist knowledge in redesigning internal and external environments is likely to be required; and on that basis, housing staff should know how to access expert advice.

Care by design – practice points[24]

Colour and contrast – strong colour and contrast can facilitate independent living as older people may experience colours as 'washed out'- different tones of grey, blue, greens and purples are harder to differentiate. Using colour and furniture that contrasts can highlight hazards and improve safety. Light Reflective Values (LRVs) can be a useful tool to maximize contrast. The most obvious example is contrasting toilet seats to make surfaces more visible. Contrast between floors and walls and walls and doors must also be considered.

Lighting – maximizing natural light is a key design feature that can help visual stimulation and movement. The choice of artificial lighting is important, with lower energy bulbs being seen as less effective. Appropriate lighting can promote independence and help sleep patterns, especially if residents have full control and choice.

Fixtures and fittings – fixtures and fittings have a significant impact on independence. Handrails and grab rails are important near stairs and steps and should be in contrasting colours. Rugs and mats should be avoided as tripping hazards, although people do feel more at home with familiar furnishings. Appropriate controls and switches are important for residents to operate them safely with larger screens and controls easier to use. Audible confirmation when things are switched on is also helpful. Light switches and electrical sockets need to be clearly visible and easily accessible.

Signage – clear, easily seen signage can help mobility and independence. Meaningful visual representations can help locate key amenities such as the bedroom or toilet more easily. Photographic signage and labels also help. Signage as a way finding tool can reduce distress in people who wander. In larger developments signage should be sited at meaningful junctions. This is especially important in sheltered accommodation where people wandering can become distressed and their resultant behaviour can impact on neighbours.

Safety – alarms and other technical systems must be easily accessible, with those featuring audible confirmation when keys are pressed being easier to use. Likewise, intercoms that can be accessed anywhere in the house and an audible warning when the door is opened can enhance a feeling of safety.

Outdoor spaces – easy access to gardens, with minimal door thresholds, make it easier for people to go outside. Well-defined paths and free-flowing loops can minimise trips. Handrails in gardens together with appropriate lighting and contrasting colors help people negotiate potential hazards.

[23] For example see: *Improving the design of housing to assist people with dementia*, DSDC, CIH, JIT (2013): http://bit.ly/2vwLsk2

[24] For more see: http://bit.ly/2xjpO3G For more on LRVs see: http://bit.ly/2yZifMB For more on colour and contrast see: http://bit.ly/1Rpn9XR

Housing practitioners should have a basic working knowledge of the range of resources and technological developments (including SMART technology) that can be used to support independent living. Frontline staff should also be aware of the technology options that are typically delivered through social work services, as well as the range of other resources that could be considered by families and carers. Alzheimer Scotland's work on dementia circles is an example of a resource for frontline housing staff. It outlines the latest developments in finding, testing and sharing everyday products that can help people affected by dementia stay independent for longer in their own homes.[25]

Stage 3: The housing suitability assessment's fit with integrated dementia care

The housing suitability assessment should be an essential component of an integrated approach to dementia care and happen as soon as possible following diagnosis. The approach should reflect the 5 and 8 Pillars Models.

If housing suitability assessments are undertaken as soon as possible following diagnosis, it will help minimise trips or falls which can result in hospital admissions and secondary complications. These complications can include a reduction in physical mobility, fear of falling/loss of confidence, avoidance of activities (for example shopping, cleaning) and the resultant loss of independence. Decreased activity can also increase joint stiffness and weakness, further reducing mobility.

To maximise the benefit of intervention, housing design changes and the provision of care, services should be planned and commissioned in parallel as set out in the 5 and 8 Pillars Models. Housing staff should encourage the involvement of care and repair services at this stage in the dementia journey.

During the research study, although examples of good practice could be cited, participants did not believe the existence of effective protocols for enabling joint early assessment of home suitability were widespread. There was also feedback that practice varied widely by council area. The perception of inconsistency seemed to apply in particular to the provision of aids and adaptations. This was both in terms of the speed of decision making and scope of what local authorities are prepared to do. Participants expressed the need for clear and unambiguous statements for service users, voluntary organisations and carers covering the service offered to people living with dementia; that advice information and support should be tenure neutral.

An effective protocol would be one which was initiated as soon as housing received notice that a tenant had had a diagnosis of dementia. This would ideally bring together the professionals involved in providing personal support together with housing, to arrange for the necessary physical alterations to the home (it was noted that such protocols were likely to apply equally to people seeking to return home from a stay in hospital). Most believed that if properly resourced, the 5 Pillars Model would perform this function in the first year, followed by the 8 Pillars Model in subsequent years.

Stage 4: The process for commissioning, funding and delivery

Housing staff should take the lead role in commissioning, funding and delivering property-related interventions and adaptations, with support from experts. Over time, other services such as health may contribute where the intervention and adaptations result in savings to their budgets.

[25] For more on Dementia Circle see: http://www.dementiacircle.org/

Housing staff should understand that the responsibility for delivering property-related interventions lies firmly with housing providers with input from design experts. This will include delivery of aids and adaptations such as multi-tonal painting and see-through cupboard doors.

Housing will generally have responsibility for funding the work, and may also be responsible for commissioning and co-ordinating. There may be potential to secure some funding from health, given the potential savings to health budgets that preventative adaptations can offer. Given the delayed discharge agenda, participants involved in the research were keen to highlight the impact of preventative housing adaptations on NHS savings.

Stage 5: Housing's role after housing suitability assessment

Housing staff should be key partners in the ongoing commitment to support people affected by dementia and their carers, in accordance with the 5 and 8 Pillars Models. They should maintain effective dialogue and engagement with customers to ensure their home continues to meet their needs.

Drawing on the 5 and 8 Pillars Models, housing staff have a key role to play in the ongoing delivery of housing information, advice and tenancy sustainment support to people affected by dementia, their carers and families. It is important, therefore, that housing staff set up and maintain effective channels of communication and information between people affected by dementia, their families and carers, and the organisations which support them. Equally important, support should include assisting in the process of obtaining necessary consents for intervention, at various stages of the process. Frontline housing and maintenance staff should be aware of basic design principles.

Frontline housing staff and others including welfare rights officers, maintenance staff and external contractors should also be trained in basic dementia awareness, to at least dementia informed practice level. [26]

Pathway 2: Practice exchange

Castle Rock Edinvar Housing Association: early assessment and adaptation of the home environment [27]

A social worker contacted the association to say that Mr B was having severe difficulties with several aspects of his property due to dementia.

Following an assessment of Mr B's home, the association made adaptations to the property to enable Mr B to remain at home safely. They included:

- light sensors which came on when someone approached – this was of huge benefit to Mr B who was having difficulty switching on the light;
- repainting – the entire property was repainted to enhance the amount of light;
- installation of grab rails; and
- a new entrance mat was provided – Mr B did not want to leave the property due to the entrance mat being a different colour.

[26] See SSSC resources on Promoting Excellence in Dementia Care: http://bit.ly/2wsSeo7

[27] For further information and other practice examples: *Housing and Dementia Programme Phase 2: Final report, Appendix 7.1: Housing and Dementia Conference Briefing Paper,* CIH (2017): http://bit.ly/2wYlMfl

The association's initial and successful experience of deploying dementia-friendly design features has resulted in the decision to invest in future-proofing the homes of other customers affected by dementia.

Viewpoint Housing Association – environmental audit

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. 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 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 2 Checklist: What housing staff should know and do when assessing whether the home environment is suitable

	What should housing staff know?	What should housing staff do?
Ensuring housing is 'bolted in' to housing suitability assessments	• Knowledge of the 5 and 8 Pillars Models. • The contribution of each agency and how each contributes to successful outcomes.	• Produce clear statements for service users and carers about the services provided. • Develop effective protocols. • Oversee the investment required to make appropriate changes in people's homes.
The key elements of a housing suitability assessment	• Basic knowledge of design that can enhance wellbeing. • Understanding how to facilitate those improvements.	• Should not reinvent the wheel – use experts where appropriate. • Accommodate tenants' personal choice, as far as possible. • Identify opportunities to build in assistive technology.
The housing suitability assessment's fit with integrated dementia care	• Understanding of role of housing suitability assessment. • Understanding of how housing suitability assessment fits with other components of dementia care.	• Produce a housing suitability assessment as soon as possible following diagnosis. • Embed design and care requirements within the 5 and 8 Pillars Models approaches.
The process for commissioning, funding and delivery	• Understanding of commissioning routes and the housing suitability appraisal process. • Awareness of key contacts, specialists and advisers. • Knowledge of assistive technology options.	• Promote housing's responsibility for delivering and funding adaptations. • Assess if health should contribute to funding. • Include needs analysis and resource requirements within the Local Housing Strategy.
Housing's role following housing suitability assessment	• Basic dementia training for housing and maintenance staff. • Extend training to external contractors, as appropriate.	• Promote housing involvement in ongoing support within the 5 and 8 Pillars Models. • Further interventions to homes to be assessed on an ongoing basis. • New homes design should be dementia friendly.

Pathway 2: Recommendations

Key recommendations for housing practitioners in **assessing whether the home environment is suitable** are as follows:

- Publicise resources which outline the services and assistance available to support people affected by dementia to live independently and well.
- Adopt planning and design guidance that supports dementia-friendly adaptations in the wider housing environment and in new-build private sector housing (see HAPPI guidance[28] and DSDC, CIH, JIT guidance[29]).
- Play a proactive role within health and social care partnerships, in order to promote the preventative benefits of housing design and allied interventions, including aids and adaptations, for people affected by dementia.

[28] *Housing our Ageing Population: Panel for Innovation (HAPPI)* (2009): http://bit.ly/2vxKxzJ

[29] *Improving the Design of Housing to Assist People with Dementia:* http://bit.ly/2vwLsk2

5. Pathway 3: Helping a person affected by dementia to remain at or return home quickly

What this pathway covers

This pathway focuses on the housing practitioner's role in delivering the interventions that support people affected by dementia to live independently. It also looks at enabling effective hospital admission and discharge processes.

Wherever possible, the aim should be to avoid hospital admission by enabling individuals to continue with their daily lives and live safely and well. Admission to hospital is often traumatic, and the longer the stay, the less likely it is that the person will return to their own home. Instead, they are more likely to be admitted to residential care. It is vital, therefore, that a person affected by dementia receives appropriate support when they are admitted to hospital, during their stay and when they are discharged home.

Pathway 3: Housing's role in helping a person affected by dementia to remain at or return home quickly

During the phase 2 study, housing staff and partners systematically explored the housing role in assisting and supporting people affected by dementia to remain at or return home quickly following hospital admission. The following conclusion was drawn:

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

Housing's role may be summarised as follows:

- To work with occupational therapists, carers and the family of people affected by dementia to understand its impact 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.
- To encourage the development of processes and systems that enable a positive 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 take an appropriate 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.
- 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.

At the frontline staff workshops, which validated the housing role, there was agreement that interaction with occupational therapists, carers and the family is a particular focus for frontline operational and frontline specialist staff. Work to integrate dementia-friendly housing design features was identified as being more typically the responsibility of managers and policy staff, given the links with financial and asset planning strategies.

Pathway 3: Practice guidance

During this research study, the nature and extent of the housing role with regards to pathway 3 were explored in detail enabling a comprehensive analysis of what housing practitioners need to know and do. The principal issues which emerged focused on the need for housing practitioners to:

- understand how to support people affected by dementia to remain at home by adapting the home environment, offering tenancy sustainment support and supporting social interaction;
- understand the importance of good communication and collaboration between housing, social care and health staff to maintain continuity of support when a person is admitted to hospital or respite services and returned home; and
- recognise that housing staff, care staff, families and unpaid carers have an important role to play in sharing their knowledge of people affected with dementia.

These are explored in more detail below.

Stage 1: Helping people affected by dementia to remain at home by adapting their housing environment

Housing staff should have a basic awareness of the signs and impairments associated with dementia and an understanding of the range of interventions to support independent living.

Frontline housing staff should receive training on the interventions, including assistive technologies that may allow people to perform tasks they could not otherwise and therefore support people affected by dementia to remain at home.[30] Health and social work colleagues stress that consistency and familiarity of the home environment are key to delivering effective adaptations which promote independent living. Put simply, dramatic changes to someone's home in terms of décor, layout or design should be avoided. This can cause unnecessary confusion or distress. Subtle changes focused on lighting, tone (for example floor coverings) and signage should be prioritised to preserve a sense of familiarity and recognition of place.

[30] For more on assistive technology see: http://bit.ly/2rvmrQJ and http://bit.ly/2w17dsG

Information sharing processes and systems that enable collaboration in adapting the home environment are critical and IT systems may need to be upgraded to enable better joint working. A clear understanding of 'consent to share' mechanisms across staff in housing, health and social work is necessary and a system of named contacts and roles across housing, health, social work and the third sector, to provide access and assistance for frontline staff, would be hugely beneficial.

Health professionals should be encouraged to recognise the important role of housing staff in supporting independent living and secure greater involvement from them to support planning and management processes.

Stage 2: Preventing health emergencies and reducing hospital admissions

Housing staff should be aware of changes in normal health and behaviour patterns and know who care managers and contacts are to ensure effective communication and information exchange on the potential risks of a health emergency.

It is not the role of housing practitioners to monitor changes in the health and behaviour of people affected by dementia. However, they should be aware of the changes in normal health and behaviour patterns that may indicate a risk of a health emergency or hospital admission and communicate changes to those leading the person's care (for example, a family member, care manager or support worker). Health and social work colleagues were keen to stress that housing staff should understand the importance of reporting such changes proactively to prevent health emergencies or hospital admissions.

Improvements in communication, processes and systems should be considered by housing services and partners to ensure an integrated approach to preventing hospital admissions, including:

- named contacts for next of kin and availability of keys; and
- awareness of any support plans in place and who co-ordinates them.

Housing interventions that can prevent a sudden escalation of symptoms and promote wellbeing at home are as follows:

- information, advice and signposting to agencies who can fund, commission and deliver preventative housing adaptations;
- information and advice on interventions to assist with physical and psychological impairment;
- safety advice, for example fire risk assessment;
- planned capital investment, for example work featuring dementia-friendly design principles;
- new-build design investment; and
- investment in assistive technology and other products that can improve the wellbeing of a person living with dementia.

Stage 3: Enabling effective hospital admission and continuity of care

Housing staff should understand the range of health services available and how to access them, as well as ensuring that on admission, family members and health and social care staff have relevant contact details for housing leads to enable early discharge planning.

The housing role in enabling access to hospital or respite care is generally a supporting one, although this principle may differ for housing support workers and frontline housing officers. During the research, housing and social work staff suggested that it is highly unlikely that frontline housing officers would be directly involved in support or care processes such as accompanying a tenant to hospital from home, even in an emergency situation. Given the more person centred remit of a housing support worker, they are more likely to be involved in this process.

For unplanned admissions, frontline housing staff can be instrumental in arranging emergency access to hospital or support services following a crisis. As well as alerting emergency support (for example arranging an ambulance or first aid care), the frontline housing practitioner has an important role to play in co-ordinating communication with those who support people affected with dementia. To do this effectively, housing staff need to ask key questions, such as: "Who is the person who knows you best?" or "Do you have a family member or support worker who helps to look after you day-to-day?"

For planned admissions, housing staff may have a role in co-ordinating admission in collaboration with health or social work services, although it would not generally be expected that housing plays a lead role.

There is unlikely to be a significant housing role while the person is in hospital except for housing- related issues. In particular, there should be an expectation that housing is informed of the discharge plan and should be involved in decision-making regarding the return to a home environment. Information sharing with colleagues must be put in place to enable this.

Of critical importance is providing assurance to people affected with dementia that they have a right to return home and the tenancy will be managed in their absence, for example:

- ensuring the rent is paid;
- ensuring the property is secure;
- ensuring housing staff know who holds keys for the property and should be contacted for access, if necessary;
- checking whether repairs or planned maintenance are scheduled and rescheduling if required; and
- ensuring accurate contact details of the person's next of kin are held.

Stage 4: Supporting effective hospital discharge

Housing staff should make contact with other agencies such as health, social work and link workers to assess the suitability of the individual's property and determine options for adaptations, technology, housing support or specialist housing.

Housing's link into the process of coordinating dementia interventions is usually through social work care managers. The research for phase 2 showed that there is a significant gap in awareness of the 5 Pillars Model and the role of link workers in planning and coordinating post diagnostic support. This should be addressed at a national level to encourage the housing sector to play an early and proactive role in delivering post diagnostic support. The earlier the timing of housing's interventions, the greater the impact on the person with dementia's ability to live independently.

The support planning for hospital discharge should ideally take place on admission. Discharge planning will be led by a specialist, most likely an occupational therapist. The person who best knows the patient should be actively involved in the planning process. Again, it is critical that effective communication channels are in place between health professionals, housing, occupational therapists and the person's link worker or next of kin.

Housing's role in support planning for hospital discharge should focus on the suitability of the person's property, for example exploring the options for adaptations, technology, housing support and/or the availability of specialist or more suitable accommodation.

Stage 5: Supporting people to remain at home and participate in their community after discharge

Housing staff should understand the links between dementia and social isolation and be aware of local opportunities for activity and involvement to inform signposting and referral. Housing staff should contribute to a person-centred plan within an integrated dementia care package.

Housing staff should understand that the housing options model can play an important role in assisting the care planning for a return home from hospital. Features include:

- a diagnostic housing needs assessment which considers both housing and underlying needs;
- a person-centred approach to defining options and potential housing solutions;
- promoting customer empowerment and encouraging choice;
- considering all options across all housing tenures and providers; and
- enabling the person to remain at home, wherever it is feasible to do so.

A key risk as dementia progresses is social isolation. Frontline housing staff should understand this as well as the benefit of encouraging engagement with social activities and wider community participation. Services such as befriending groups and activity centres can be important in building confidence and trust and in enabling a person with dementia to avoid isolation.

Pathway 3: Practice exchange

Trust Housing Association: Helping a person affected by dementia to remain in a home environment[31]

Mrs C's application for sheltered housing noted her dementia diagnosis. She was a homeowner and isolated in the community. Her family had submitted a sheltered housing application due to concerns about her isolation and nutrition as she was not eating well.

Due to her level of need, a home visit was conducted before Mrs C was offered a tenancy. A personal plan was completed at the start of her tenancy to address her specific support requirements, including a prompt to attend for meals and orientation of the building.

At the three month review of Mrs C's personal plan, the need for further assistance in some areas was identified including:

- taking medication;
- bathing;
- signage to identify toilets, lift floors and dining room; and
- encouragement to eat in the dining room at meal times and socialise in the lounge area to avoid isolation.

Based on a comprehensive and ongoing assessment of Mrs C's changing support needs and the range of interventions put in place, Mrs C is able to live independently within sheltered housing, with notable improvements in her health and wellbeing.

Castle Rock Edinvar Housing Association: Adaptation of current accommodation

Following an assessment of the suitability of Mr B's home, the 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;
- repainting the property internally to enhance the amount of light;
- installing grab rails in the bathroom, in a contrasting colour to the walls for easy visibility; and
- changing the entrance mat to the same colour as the rest of the floor coverings so that it was not 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.

[31] For further information and other practice examples: *Housing and Dementia Programme Phase 2: Final report, Appendix 7.1: Housing and Dementia Conference Briefing Paper*, CIH (2017): http://bit.ly/2wYIMfl

Pathway 3 Checklist: What housing staff should know and do to help a person affected by dementia to remain at or return to home quickly

	What should housing staff know?	What should housing staff do?
Enabling a person affected by dementia to remain at home by adapting their housing environment	• Awareness of the signs, signals and impairments associated with dementia. • Understand the range of interventions that can be pursued and how to action. • Awareness of the 5 Pillars Model.	• Implement housing design changes, assistive technology and a holistic housing needs assessment. • Aim to have dementia-friendly design features in new developments. • Communicate with health, social care, people affected by dementia and family/ carers.
Preventing health emergencies and reducing hospital admissions	• Awareness of signs and symptoms that indicate a person with dementia is at risk of a health emergency or hospital admission. • Awareness of housing interventions that can prevent sudden escalation of symptoms.	• Communicate changes in normal health and behaviour patterns to social care contacts. • Signpost people affected by dementia to social groups and community networks to avoid isolation. • Implement adaptations and provide safety advice.
Enabling effective hospital admission and continuity of dementia care	• Know key questions that would help a person with dementia on admission. • Understand the range of health services available to provide support in a home environment and how to access them.	• Communicate housing issues. • Share housing contact information with health and social care to enable an early approach to discharge planning. • Protect housing status of a person admitted to hospital.
Supporting effective hospital discharge	• Awareness of need to share contact details of housing leads with partners to support discharge planning. • Awareness of housing's role in support planning for hospital discharge via housing suitability appraisal.	• Ensure that the return home is a success by determining options for adaptations, housing support, or the availability of more suitable accommodation. • Communicate with the person with dementia, their family/carers and health and social care colleagues.
Post discharge - supporting people to remain at home and participate in their community	• Know the links between dementia and social isolation. • Understand the local network of support services to encourage engagement.	• Use housing options approach for care planning • Engage with dementia friendly initiatives. • Encourage staff to undergo appropriate level of training, for example SSSC Promoting Excellence and use of related materials.

Pathway 3: Recommendations

Key recommendations for housing practitioners **to help a person affected by dementia to remain at or return home quickly** include:

- Focus on preventative solutions which encourage early action; improve housing suitability and independence and support effective admission, discharge and resettlement.
- Recognise and promote the role of the housing professional in delivering these preventative solutions.
- Adopt and develop the use of the housing options model to deliver positive outcomes for people affected by dementia, ensuring housing staff are fully trained and confident in its use.
- Adopt and develop a clear process for sharing information about people affected by dementia.
- Improve awareness of dementia practice, particularly in relation to Alzheimer Scotland's 5 and 8 Pillars Models of dementia care.
- Work with health sector colleagues to develop a clear role for the housing practitioner in signposting customers to general health screening including well women/well man assessments, living well services, advice on diet or exercise etc.

6. Pathway 4: Ensuring holistic assistance and support as dementia progresses

What this pathway is about

This pathway focuses on a holistic approach to all aspects of support as dementia progresses. It has an organisational as well as a housing practitioner focus. Embedded in the community, housing practitioners can play a vital role by engaging with the agencies that co-ordinate dementia care and promoting the delivery of housing-led interventions.

Housing organisations should promote basic awareness of dementia for all staff, including at strategic and leadership levels, in order to promote a proactive housing role to dementia care. Aligned to this, staff should be aware of the growing body of housing and dementia learning materials available and use them to continuously develop and improve practice.

Pathway 4: Housing's role in ensuring holistic assistance and support as dementia progresses

Pathway 4 focuses on the housing role in promoting a holistic approach to dementia care. It focuses on the resources available to housing staff to help them make a positive contribution to dementia care. It encourages housing organisations to invest in staff learning and development, operational policies and joint working partnerships. This includes engagement with agencies who co-ordinate dementia care and people affected by dementia themselves.

During the phase 2 study, housing staff and partners systematically explored the housing role in ensuring holistic consideration of assistance and support as dementia progresses and came to the following conclusion:

> Housing staff 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 learning and development opportunities, develop policies and promote dementia awareness.

Housing's role may be summarised as follows:

- To ensure basic dementia awareness and an understanding of the role of housing staff and services in meeting the needs of people with dementia is achieved at all levels within housing organisations.
- To assess the learning and development 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, providing person-centred information and advice.
- 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.
- To share emerging practice in meeting the needs of people with dementia across the housing sector and dementia partners.

Pathway 4: Practice guidance

During this research study, the nature and extent of the housing role with regards to pathway 4 were explored in detail enabling a comprehensive analysis of what housing practitioners need to know and do. The principal issues which emerged focused on the need for housing organisations and staff to:

- increase levels of knowledge and understanding;
- know how to access and use key learning resources; and
- understand what it means to take a holistic approach to developing strategies for people affected by dementia.

These are explored in more detail below.

Stage 1: What should housing staff know about dementia?

Housing organisations should increase levels of dementia awareness across all housing staff, with enhanced levels for specialist staff. They should consider creating dementia champions to lead delivery of positive dementia practice within the workplace.

In order to deliver holistic assistance and support as dementia progresses, all housing staff should possess a basic level of dementia awareness. An understanding of dementia at every level in a housing organisation is a key aspect to ensuring that staff play an appropriate role in dementia care. Housing organisations should also review service standards, to ensure that dementia issues are embedded within their approach to customer care.

Learning and development strategies should focus on the principle that a basic level of dementia awareness is desirable for all housing staff. This includes all frontline workers in maintenance, technical, estate management, support, regeneration and customer care roles. External contractors and tradespeople should also have the opportunity to be involved.

As a minimum, all staff should be trained to SSSC Promoting Excellence Dementia Informed Practice Level.[32] Advanced levels of knowledge and skills development will be appropriate for specialist staff who have regular contact with people affected by dementia.

[32] See SSSC resources on Promoting Excellence in Dementia Care: http://bit.ly/2wsSeo7

Stage 2: Key learning materials to assist staff to deliver a holistic approach for people affected by dementia

Housing staff should be encouraged to access key learning and development materials (including materials from DSDC, SSSC, Alzheimer Scotland and Age Scotland).

Appropriate learning materials should be available to all frontline housing staff, enabling them to make a positive and effective contribution to meeting the needs of people affected by dementia.

Key training resources and materials include:

- Dementia Friends Scotland: online or face-to-face sessions www.dementiafriendsscotland.org; dementiafriends@alzscot.org.
- Promoting Excellence resources: www.sssc.uk.com/workforce-development/supporting-your-development/promoting-excellence-in-dementia-care.
- DSDC resources: dementia.stir.ac.uk/housing-dsdc/education-and-housing, including:
  - Dementia design audit tool; and
  - Improving the design of housing to assist people affected by dementia.
- Age Scotland resources: www.ageuk.org.uk/scotland/about-us/our-work/early-stage-dementia-project/raising-awareness-for-workplaces/.
- Alzheimer's Society material and practice guides, including:
  - How to become dementia-friendly: Tips for businesses and organisations;
  - How to help people affected by dementia: A guide for customer-facing staff;
  - Dementia-friendly technology; and
  - Creating a dementia-friendly workplace.
- Dementia Friendly Communities: Environmental Assessment Tool.

Housing staff should have a basic understanding of the 5 Pillars Model and how to access information on named persons at a local level (the co-ordinators of post-diagnostic support planning). Housing staff should have a sound working knowledge of the distinction between the 5 and 8 Pillars Models of dementia practice.

Stage 3: Key components of effective strategy to deliver holistic approach to people affected by dementia as condition progresses

Housing organisations should develop dementia strategies which encourage integrated care, promote independent living, deliver housing options and link to asset management strategies.

All housing providers should develop a dementia strategy which is proportionate to the size of the organisation and to the customer group they serve. Key objectives of any housing and dementia strategy should be a focus on the benefits of an integrated approach to

dementia care, including partner collaboration, enhanced prevention, the promotion of independent living and a dementia-sensitive approach to customer care.

Housing providers should consider how operational policies and procedures can be 'dementia- proofed' as part of a wider dementia-friendly agenda and how dementia-friendly design principles can be considered within housing capital programmes, asset management strategies and housing office environments, such as reception areas.

Staff should understand the role of housing services in enabling independence for people affected by dementia, and ensure that a holistic approach to dementia care is achieved by collaborating with other agencies, building strong local networks and proactively engaging with people affected by dementia, their carers and support groups in service planning and delivery.

During the research, health and social work colleagues highlighted the following issues:

- The importance of training, early intervention, assistive technology and communication with people affected by dementia across housing services will be instrumental in building the housing role in dementia care.
- Learning and development in housing should focus on the principle that a basic level of dementia awareness is desirable for all housing staff but higher levels are appropriate for specialist colleagues who have regular contact with people affected by dementia.

Pathway 4: Practice exchange

Trust Housing Association: An integrated approach to dementia care

Mr F had applied for long-term care as he was struggling to cope in his home. However, a social work assessment confirmed he did not meet the criteria for long-term care and health colleagues felt that, due to his dementia, the best option would be for him to remain in his home where there is familiarity. A housing options project officer arranged a case conference with his family and all the partners involved. As a consequence, a number of measures were put in place to support Mr F, including an application to the Scottish Welfare Fund to replace furnishings and fittings damaged in a fire, and adaptations to address his disabilities.

The plan that Mr F would move on to sheltered housing has been put on hold as he is currently thriving in his home environment, whilst receiving housing support.

A number of agencies have been involved in delivering an integrated approach to Mr F's dementia care, including:

- housing options for older people project officer;
- register social landlord colleagues;
- health colleagues;
- social worker; and
- Scottish Welfare Fund.

Abbeyfield Scotland: Involving other agencies[33]

Abbeyfield Scotland 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.

[33] For further information and other practice examples: *Housing and Dementia Programme Phase 2: Final report, Appendix 7.1: Housing and Dementia Conference Briefing Paper*, CIH (2017): http://bit.ly/2wYIMfl

Pathway 4 Checklist: what housing staff and organisations should know and do to ensure holistic consideration of assistance and support as dementia progresses

	What should housing staff know?	What should housing staff do?
What should housing practitioners know about dementia?	• Greater level of general dementia awareness and training across all housing staff. • Specialist staff should have higher levels of dementia awareness and training.	• Housing organisations should encourage dementia champions to set an example for others.
What should a dementia training strategy include?	• Basic dementia training which focuses on customer care, provided to all staff. • SSSC Promoting Excellence training encouraged.	• Effective training, early intervention, regularly engaging with people affected by dementia and implementing housing interventions. • Understand and engage with the 8 Pillars Model of integrated dementia care.
What will assist staff in delivering a holistic approach to people affected by dementia?	• How to utilise DSDC, SSSC, Alzheimer Scotland and Age Scotland learning materials and resources. • Ability to engage with dementia support units in hospitals when required.	• Implement housing options approach in integrated approach to dementia care. • Understand principles of *Scotland's National Dementia Strategy 2017-2020.*
How should the 5 and 8 Pillars Models approaches be used?	• Understand distinction between the 5 and 8 Pillars Models and how the housing role fits. • Awareness of one year post diagnosis support that comes with the 5 Pillars Model.	• Promote the benefits of an integrated approach to dementia care and the housing role. • Retain the principles and objectives of the DPC.
How can a strategy be developed which delivers a holistic approach as the condition progresses?	• Importance of organisational strategy and policies to support people affected by dementia. • Operational policies and procedures to promote positive housing outcomes in meeting the needs of people affected by dementia.	• Work with others to promote housing options approach. • Establish robust data on the scale of issues associated with housing and dementia. • Encourage strategic links between capital programmes and asset management strategies.

Pathway 4: Recommendations

Key recommendations for housing organisations and their staff to ensure **holistic assistance and support** as dementia progresses include:

- Prioritise dementia awareness, learning and skills development across every aspect of housing services to enable frontline, support, managerial and leadership staff to play a proactive role in dementia care, for example through SSSC Promoting Excellence resources.
- Improve awareness of dementia practice, particularly in relation to Alzheimer Scotland's 5 and 8 Pillars Models of dementia care.
- Raise awareness of dementia-friendly communities through community engagement activity.
- Engage in development work between housing and health sectors on the role of the housing worker in signposting customers into preventative health services.
- Develop a clear process for sharing information about people affected by dementia across public services and the third and voluntary sectors involved in dementia care.

7. Conclusion

The housing and dementia programme represents a significant analysis of the housing sector's engagement in dementia care and the potential to do more – to make a real difference to people's lives. Phase 2 drew on the expertise of a broad range of housing staff and partner organisations across Scotland to develop a clear role for housing in supporting people affected by dementia. This represents a vision for housing's vital contribution to one of the 21st century's biggest challenges. It is imperative that this potential is understood and realised by housing professionals and their partners in government, public and third sectors.

Phase 2 was an interactive process, incorporating the views, experiences and expectations of the study participants. We expect the housing role as set out in this practice guide to continue to evolve within a broad range of local situations and as policy, practice and technology develops.

Each of the pathways chapters includes detailed recommendations which we will not repeat here. However, the following key messages summarise what housing practitioners in Scotland can do to make a real difference to people affected by dementia, their families and carers:

- Accept that the scale of dementia as a major societal challenge requires a higher level of strategic and frontline priority from housing organisations.
- Understand the nature and extent of their role in dementia care and develop the knowledge and skills required to successfully fulfill this.
- Use a housing options approach to facilitate independent living.
- Develop effective partnership working arrangements with colleagues across the housing services and other organisations to maximise the quality of outcomes.
- Promote housing's wider role in enabling independence beyond the physical and home environments to partner organisations.

Housing practitioners, working with their partners, are well-placed to lead meaningful change in the way people live with dementia while improving community understanding and acceptance. Preventative tenancy sustainment keeps people living at home safely for as long as possible and the promotion of positive interaction and dementia-friendly communities build cohesion, while breaking down the stigma associated with the condition.

Housing practitioners are well used to difficult challenges – they are in the business of making their corner of the world a better place. We hope this practice guide supports your endeavors in making the world a better place for people affected by dementia, their families and carers.

Appendix: Useful resources

Age Scotland materials and resources

www.ageuk.org.uk/scotland/about-us/out-work/early-stage-dementia-project/raising-awareness-for-workplaces/

Alzheimer Society materials and resources

https://www.alzheimers.org.uk/

Alzheimer Scotland materials and resources

https://www.alzscot.org/

Alzheimer Scotland's 5 Pillars Model of post-diagnostic support

http://www.alzscot.org/campaigning/five_pillars

Alzheimer Scotland's 8 Pillars Model of integrated dementia care

http://www.alzscot.org/campaigning/eight_pillars_model_of_community_support

CIH Scotland Housing and Dementia Programme

http://www.cih.org/scotland/housing_dementia_prog

DSDC materials and resources

dementia.stir.ac.uk/housing-dsdc/education-and-housing

Guide to positive language to use when speaking about dementia

https://www.alzheimers.org.uk/info/20064/symptoms/90/communicating_and_language

http://dementiavoices.org.uk/wp-content/uploads/2015/03/DEEP-Guide-Language.pdf

http://www.nhs.uk/Conditions/dementia-guide/Pages/dementia-and-communication.aspx

Healthcare Improvement Scotland's Improvement Hub (ihub)

http://ihub.scot/focus-on-dementia/

Principles of the Triangle of Care

https://www.rcn.org.uk/clinical-topics/dementia/triangle-of-care

https://my.rcn.org.uk/__data/assets/pdf_file/0009/549063/Triangle_of_Care_-_Carers_Included_Sept_2013.pdf

Scotland's National Dementia Strategy and wider policy framework on dementia

http://www.gov.scot/Topics/Health/Policy/Dementia

https://beta.gov.scot/publications/scotlands-national-dementia-strategy-2017-2020/pages/1/

SSSC Promoting Excellence resources

www.sssc.uk.com/workforce-development/supporting-your-development/promoting-excellence-in-dementia-care;

Dementia Pathways Housing's Role Practice Guide

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.

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