1. Workshop 1: Assisting & Supporting Dementia Diagnosis

Arneil Johnston, independent housing consultancy, has been commissioned by the Chartered Institute of Housing to conduct research for the second phase of their successful Housing and Dementia Programme. This second phase will focus on improving links between housing organisations and partners in health, social care and the third sector, with a specific focus on the role of the housing professional in meeting the needs of those living with dementia.

As part of this research, Arneil Johnston hosted a series of stakeholder events throughout the summer with a specific focus on:

- examining key interactions, processes and pathways;
- examining the role of the housing professional in dementia pathways; and
- housing’s role in building awareness and acceptance of dementia.

The first round of these stakeholder engagement events were held in July 2016 and focused on bringing together professionals across housing, health, social care and dementia services to analyse and define the links, relationships and pathways associated with the following common interactions:

1. assisting and supporting someone to seek a diagnosis;
2. early assessment of the suitability of someone’s home;
3. identifying appropriate changes to enable the person with dementia to remain at home/be returned home quickly;
4. ensuring holistic consideration of all aspects of assistance/support as dementia progresses.

The first of these workshops, was held on Monday 4th July 2016 and focused on the service pathway associated with assisting and supporting someone to seek a diagnosis. Arneil Johnston facilitated the session, guiding partners through an interactive mapping process to gain a clear understanding of:

- service access, inter-relationships and processes;
- diagnostic (& holistic) risk assessment and management;
- data collection/sharing processes to aid service response and/or referral (with a focus on confidentiality and consent);
- optimum service pathways which are preventative, person centred and offer choice;
- maximising resources and client outcomes through multi-agency collaboration.
The workshop was held from 10.00am till 3.30pm and was based on the following programme:

<table>
<thead>
<tr>
<th>Timing</th>
<th>Activity</th>
<th>Nature of Activity</th>
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<tbody>
<tr>
<td>10.00 – 10.20</td>
<td>Introduction &amp; Welcome</td>
<td>AJ led briefing session</td>
</tr>
<tr>
<td>10.20 – 10.45</td>
<td>Session 1: Assessing the changing agenda</td>
<td>Focus group discussion</td>
</tr>
<tr>
<td>10.45 – 12.15</td>
<td>Session 2: Assisting &amp; supporting diagnosis: what should happen in an ideal world?</td>
<td>Interactive activity</td>
</tr>
<tr>
<td>13.00 – 13.45</td>
<td>Lunch</td>
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<tr>
<td>14.30 – 15.15</td>
<td>Session 5: What needs to happen to move from reality to ideal world?</td>
<td>Interactive activity</td>
</tr>
<tr>
<td>15.15 – 15.30</td>
<td>What happens next &amp; close of session</td>
<td>AJ led briefing session</td>
</tr>
</tbody>
</table>

The following professionals participated in the workshop session:

- Paul Callaghan, North Lanarkshire Health & Social Care Partnership;
- Ann Marie Clark, North Lanarkshire Council;
- Samantha Flower, NHS Greater Glasgow & Clyde;
- Karen Heath, Ceartas;
- Michelle Higgins, Horizon Housing Association;
- Owen Miller, Alzheimer Scotland;
- Margaret Moore, CIH Scotland;
- Susan Morris, South Ayrshire Council;
- Elaine O’Hanlon, Link Housing Association;
- Angela Gardiner, Help to Adapt (Link Housing Association);
- Ellen Thompson, East Renfrewshire HSCP; and
- Helen Thomson, Bield Housing and Care.

This briefing paper presents the outcomes from Workshop 1, which focused on assisting and support someone to seek a diagnosis of dementia.
2. **Session 1: Assessing the changing agenda for housing & dementia**

Following a short introduction that set out the background, context and pathway under consideration in Workshop 1; participants engaged in discussion on the extent to which the overall agenda has changed since Phase 1 of the research and the publication of “Improving Housing and Housing Services for People with Dementia: Housing and Dementia Survey” in 2013.

To enable this, Arneil Johnston provided an overview of the context and outcomes of Phase 1 of the CIH Housing & Dementia Programme, followed by group discussion of the following questions:

- What impact has health and social care integration had on the overall housing and dementia agenda?
- What impact will the 3rd National Dementia Strategy have on the housing and dementia agenda?
- How have housing contribution statements taken forward the dementia agenda in Scotland?

In the course of discussion and review the group suggested that:

- The diversity of locality and integration arrangements across the country had made it more complex to exert influence.
- There was a mixed picture in terms of the benefits of integration, though some definite examples of good practice.
- The link into joint boards had led to improvements in communications, making minutes and materials more accessible.
- The testing of the ‘8 Pillars’ model had been useful leading to significant success and good practice in Glasgow with the development of the ‘Glasgow Dementia Strategy’. It is important that this priority is sustained beyond the testing phase.
- There is a greater accountability in the system with health ‘answerable’ to joint boards which have elected members serving on them.
- There was limited knowledge about what housing does. Although it was acknowledged that both the ‘housing contribution statement’ was useful in improving this situation and that there is a responsibility on housing to clearly think through what its contribution is.

3. **Introducing pathway 1: Assisting and supporting someone to seek a diagnosis of dementia**

To support Arneil Johnston to assemble a series of conversation starters on each aspect of how to assist and support someone to seek a diagnosis of dementia; the Dementia Services Development Centre (DSDC) at Stirling University provided the following material to stimulate debate and to highlight the knowledge requirements of frontline housing staff:
Assisting & supporting dementia diagnosis

The role of Housing in supporting & assisting early diagnosis
Getting diagnosed as early as possible increases the time when people can concentrate on spending time with the people they love doing the things that matter most to them.

Early diagnosis also allows people to access treatments at a time when they can be most impactful, and utilise support services both for themselves and for their loved ones.

One of the biggest advantages of early diagnosis is that the individual can have an active voice in making decisions for care and support in the future.

What do Housing practitioners need to know to support early diagnosis?
1. Challenges for someone with dementia to maintain housing status
2. Recognising the potential signs of dementia
3. Understanding the diagnosis pathway and how to signpost/support someone to enter that pathway
4. Awareness of local support services for newly diagnosed individuals
5. Communication skills: how to have difficult conversations regarding the potential need for diagnosis
6. Building relationships/trust
7. Co-production of decision making and supporting client involvement
4. Session 2: Assisting & supporting diagnosis: What should happen in an ideal world?

The aim of this central session was to analyse and define the links, relationships, processes and pathways for referrals to/from housing organisations when assisting and supporting someone to seek a diagnosis of dementia. To achieve this, through discussion, workshop participants mapped out the interactions, activities and recommended practice associated with the following question:

“In an ideal world, and working in partnership with health, care and support agencies, how can housing organisations assist and support someone to seek a diagnosis of dementia?”

Using research evidence, best practice material and relevant guidance on assisting and supporting a dementia diagnosis, the following ‘best practice pathway’ was drafted in five stages for further examination by workshop participants.

1. Triggers, signals or problems that suggest the need for diagnosis
2. Signs & symptoms that check/confirm diagnosis may be of benefit (i.e. what is/is not dementia)
3. Engaging & encouraging diagnosis: what language to use/what to ask
4. Making a referral & how to do this effectively
5. The housing role post diagnosis - how do practitioners enable risk?

Each stage in the best practice pathway was presented on an exhibition board together with discussion questions and relevant research or best practice material; to stimulate thinking, debate and validate the pathway.

Taking each stage of the pathway in turn, participants used best practice evidence and group consensus to map/validate/design how housing practitioners should support and enable someone to seek diagnosis. Where gaps in best practice or research were identified, this was noted and addressed through discussion, with participants also testing and validating research findings and recommended practice.

The outcomes for each stage of the interaction to support and assist someone to seek a diagnosis of dementia were as follows:
4.1. **Stage 1: Triggers, signals or problems that suggest the need for diagnosis**

Through discussion, participants examined stage 1 in the pathway defining the (i) knowledge requirements; (ii) practice recommendations; and (iii) partnership actions associated with:

1. encouraging early diagnosis; and
2. identifying the triggers or signals that suggest diagnosis may be beneficial.

<table>
<thead>
<tr>
<th>What triggers should lead a housing practitioner to consider that a dementia diagnosis may be necessary i.e. what problems may a person with dementia be facing?</th>
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</thead>
</table>
| Firstly housing staff should have a clear baseline understanding of the natural ageing process and how it may affect the day to day lives of older people. Beyond this, there are a number of triggers which housing staff should be aware of that could help to detect changes in a person's mood, behaviour, ability to interact with others and/or home environment. In simple terms these triggers could be categorised as (i) personal triggers; and (ii) property triggers. Personal triggers which suggest changes that could be dementia related include:  
  - signs of stress, paranoia or anxiousness;  
  - 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;  
  - a change in the way someone interacts with their partner. Property triggers which suggest changes that could be dementia related include:  
  - more or less interactions with housing services than normal – simply being less visible than normal;  
  - changes in rent payments particularly when there have been consistent patterns of behaviour;  
  - changes to the normal state of someone’s garden or home (e.g. less tidy, more cluttered);  
  - an increase in response repairs due to flooding, fires or other hazards that would normally be avoided;  
  - more instances of leaving the door open or the property being obviously insecure. |

<table>
<thead>
<tr>
<th>Knowledge requirements</th>
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</table>

- Impairment of memory:
  - Increasing difficulty in remembering recently acquired information
  - Difficulty recognising friends and family
  - Forgetting names of friends and common objects

- Impairment of reasoning:
  - Difficulty in working things out
  - Not being able to use a new design of kitchen appliance
  - New-found difficulty handling money

- Impairment of learning:
  - Inability to learn or remember names of people or objects
  - Repetitive questioning due to inability to remember the answer
  - Problems learning how to learn to use new objects

- Increased stress levels:
  - Becoming distressed if you are in an unfamiliar environment
  - Anxiety from not recognising people
  - Inability to recognise, understand or adapt to what’s going on around

- Reduced capacity to deal with age-related changes:
  - Forgetting to use recently acquired prosthetics, e.g., glasses or hearing aids
  - Neglecting to keep the house warm
  - Forgetting to eat or drink enough fluids

What does a housing professional need to know about the importance of early diagnosis and how to encourage early engagement?

There are key knowledge requirements on the benefits of early diagnosis that frontline housing professionals should be aware of which can be best summarised by the following material provided from DSCS:

- Getting diagnosed as early as possible increases the time when people can concentrate on spending time with the people they love doing the things that matter most to them.
- Early diagnosis also allows people to access treatments at a time when they can be most impactful, and utilise support services both for themselves and for their loved ones.
- One of the biggest advantages of early diagnosis is that the individual can have an active voice in making decisions for care and support in the future.

- Early provision of support at home can actually decrease institutionalisation by 22% (NHF).
- Only 21% of people with dementia have their dementia diagnosed before hospital admission.
- 1/3 people with dementia waited longer than a year to go to their GP.
Whilst frontline housing staff have a unique opportunity (and generally a keen perceptiveness) to spot triggers or signals that indicate diagnosis could be of benefit; staff don’t always connect these triggers to dementia or know how to encourage diagnosis.

It is likely that frontline housing staff may not see encouraging dementia diagnosis as part of their role. Key messages for practice recommendations are as follows:

1. The role of the frontline housing officer is to signpost customers into services that could support wellbeing and tenancy sustainment (not to spot and diagnose dementia). This includes signposting to services that encourage or provide dementia diagnosis;

2. Frontline housing & technical staff should be assured of their ability to make a difference by taking appropriate action to encourage early diagnosis and kick start the process of identifying a range of options that could support independent living and wellbeing;

3. Frontline staff need to be equipped with skills in how to manage sensitive conversations on dementia diagnosis. Key practice points include:
   - If you suspect that diagnosis should be encouraged, approach conversations and interactions with sensitivity but take action;
   - In interactions, don’t use the word dementia;
   - Understand the stigma associated with the condition and how this affects engagement with services that provide diagnosis;
   - Accept there may be resistance to accepting help or engaging with services;
   - Be positive and solutions focused, highlighting the range of support and interventions that can enable independent living for older people.

### 4.2. Stage 2: Signs & symptoms that check/confirm diagnosis may be of benefit (i.e. what is/is not dementia)

Through discussion, participants examined stage 2 in the pathway defining the (i) knowledge requirements; (ii) practice recommendations; and (iii) partnership actions associated with the:

1. signs and signals associated with dementia (and not other conditions/illnesses); and

2. questions a housing practitioner should ask to assess the need for a dementia diagnosis.
**What signs & signals suggest that a person may have dementia (and not other conditions/illnesses)?**

There are key knowledge requirements on the signs and signals associated with dementia which can be best summarised by the following material provided from DSCS:

<table>
<thead>
<tr>
<th>A person with dementia may seem:</th>
<th>A person with dementia may also:</th>
</tr>
</thead>
<tbody>
<tr>
<td>• apathetic</td>
<td>• be forgetful of recent events</td>
</tr>
<tr>
<td>• less interested in hobbies or activities</td>
<td>• be repetitive in speech or actions</td>
</tr>
<tr>
<td>• unwilling to try new things</td>
<td>• be confused regarding time and place</td>
</tr>
<tr>
<td>• unable to adapt to change</td>
<td>• be neglectful of hygiene or eating</td>
</tr>
<tr>
<td>• less able to make decisions or plans</td>
<td>• become angry or distressed very rapidly</td>
</tr>
<tr>
<td>• slower to grasp complex ideas</td>
<td>• see or hear things that are not there</td>
</tr>
<tr>
<td>• ready to blame others for ‘stealing’ mislaid items</td>
<td></td>
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<tr>
<td>• more self-centred</td>
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Frontline staff should also have a basic awareness of the distinguishing characteristics of delirium, dementia and depression to guide thinking and interactions.

In terms of spotting and interpreting signs and signals that could suggest the need for dementia diagnosis, the key point is that frontline staff detect changes from normal behaviour which are consistent in their pattern, i.e. a change in mood, behaviour, interactions or property standards which are prolonged and notable over a reasonable period of time (weeks, months — not days).

**Knowledge requirements**

In terms of interpreting signs and signals, frontline staff can confirm whether changes in a person are obvious to them or have been stimulated by a key life event (experiencing bereavement). Simple, informal interactions can help build a picture of whether signs and signals are dementia related and initiate dialogue which encourages the person to act on changes they have been experiencing.

Staff should keep dialogue light, informal and ask simple questions about the person’s physical health, e.g.

- 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 which works for the customer and carried out with sensitivity.

Housing staff should note that respecting the person’s right to give you 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 changes or avoid conversations on this topic.

**Practice recommendations**
### What questions should the housing practitioner ask to assess the need for a dementia diagnosis or to assess the risks facing that person?

<table>
<thead>
<tr>
<th>Practice recommendations</th>
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<tbody>
<tr>
<td>There are a number of simple questions which would enable the frontline housing professional to assess the person’s ability to live safely and independently (which dovetails strongly with proactive tenancy management practice):</td>
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<tr>
<td>- Do you get help or support from anyone with day to day living?</td>
</tr>
<tr>
<td>- Who offers this help and why?</td>
</tr>
<tr>
<td>- How are partners or carers, i.e. are they (coping) well?</td>
</tr>
</tbody>
</table>

These interactions should be carried out with respect, sensitivity, compassion and with the lightest touch possible. Should a person need to access a dementia diagnosis, it is hugely important to encourage engagement by building trust.

Frontline housing staff should encourage older people to think about the future and how their needs could change. Older people should be encouraged wherever possible to think about future housing, care and support plans. To support this, staff should be equipped to offer information on the range of options that could be available to support independent living and the practical help and advice available to assist with decision making.

There should be confidence that if a frontline member of staff is concerned or worried about an individual and suspects that dementia diagnosis may be beneficial, it is legitimate to act on these concerns.

Frontline housing & technical staff need to understand the pathway for channelling concerns that a person would benefit from dementia diagnosis.
4.3. **Stage 3: Engaging & encouraging diagnosis: what language to use/what to ask**

Through discussion, participants examined stage 3 in the pathway defining the (i) knowledge requirements; (ii) practice recommendations; and (iii) partnership actions associated with:

1. encouraging diagnosis: positive language and communication;
2. person centred service interactions – building trust & offering choice; and
3. entry & decision making in the dementia diagnosis pathway.

<table>
<thead>
<tr>
<th>What is the best approach to communicating or having difficult conversations on the potential need for diagnosis with (i) the person; (ii) their family/carer(s)?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Knowledge requirements</td>
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<tr>
<td>Practice recommendations</td>
</tr>
</tbody>
</table>

There are key knowledge requirements on the acceptable language to use when talking about dementia which can be best summarised by the following material provided from DSCS:

<table>
<thead>
<tr>
<th>Words to Avoid</th>
<th>Alternative Words</th>
</tr>
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<tbody>
<tr>
<td>Dementia sufferer; demented, senile or senile dementia, burden e.g. people cause a burden, victim, plague, epidemic, living death e.g. dementia is a living death</td>
<td>Person/people with dementia Person/people living with dementia Person/people living well with dementia</td>
</tr>
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</table>

Frontline staff should be aware of the importance of building trust to enable successful conversations on dementia diagnosis to take place. Key practice points to guide communication on dementia diagnosis include:

- recognise problems that the person may be facing with day to day living but always in the context of the solutions that may be available to address those problems;
- discussing options and being solutions focused often enables trust to be established and other issues to be shared and identified;
- to win someone over, being positive and highlighting the benefits of engagement is crucial;
- use simple, clear and direct language e.g. “I think you would benefit from talking to your GP about this”;  
- **do not** use the word dementia in these interactions.
Who is & should be involved in decision making processes for dementia diagnosis?

Given the signs, symptoms and profile of those who may be at risk of dementia, and the opportunities for engagement afforded by proactive tenancy management; there could be a future housing led role in enabling a more assertive outreach approach to having conversations about dementia diagnosis.

Where possible, the individual themselves should be encouraged and enabled to seek diagnosis. On this basis, staff should have basic knowledge on the dementia diagnosis pathway and be clear that diagnosis starts with GP engagement.

Housing staff should signpost an individual into the diagnosis pathway, considering whether the provision of support or advocacy may be appropriate. As it is not expected that frontline housing staff would provide this support or advocacy, if referrals are made to health, care or support agencies, this must be achieved by attaining the consent of the individual.

If a person is resistant to engaging in any dialogue about dementia diagnosis and it is not possible for a housing professional to encourage entry to the diagnosis pathway; if outstanding concerns remain regarding the wellbeing or safety of that person, it may be appropriate to engage with carers or family. It is therefore important, that where possible, the housing professional builds up knowledge of the network that supports the individual. To achieve this, housing professionals should have awareness of the principles of the ‘triangle of care’, which is a model which encourages engagement between professionals and their carers. Using the standards and principles of this model will enable housing staff to ensure that confidentiality and information sharing requirements are not breached in their engagement with carers.

Without disclosing personal information, housing staff, where it’s possible to do so 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 social work services. Understanding the adult protection process and pathway is therefore a key knowledge requirement for frontline housing staff.
How do we encourage a co-production of decision making & supporting client involvement?

In making a decision to enter the dementia diagnosis pathway, wherever possible, housing’s role is to encourage the individual themselves to make decisions and take action and to enable this through signposting to practical support, care and advocacy services.

Where it has been possible to discuss dementia – either because the individual themselves has raised concerns or used the word, the frontline housing professional should provide information on the benefits of early diagnosis through GP engagement. Under these circumstances, it may be appropriate to signpost the individual to materials or services that could offer support including those provided by Alzheimer Scotland.

In ordinary circumstances, housing professionals should be encouraged to share information on the benefits of regular health screening in promoting wellbeing so that, wherever possible, the person can take early action to maintain independence and become involved in decision making on the options available to enable this.

4.4. Stage 4: Making a referral & how to do this effectively

Through discussion, participants examined stage 4 in the pathway defining the (i) knowledge requirements; (ii) practice recommendations; and (iii) partnership actions associated with the:

1. referral and consent processes associated with diagnosis pathway; and
2. communication & collaboration across partners to deliver care, support and housing options.

How & to whom should a referral for dementia diagnosis be made?

Frontline housing staff should have clarity that their role is to encourage a person to take action themselves in seeking diagnosis through active signposting into health services. There is no mechanism in place which enables frontline housing staff to make referrals for dementia diagnosis.

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

1. the intervention of housing professionals encourages and motivates an individual to make a self-referral to their GP for dementia diagnosis;
2. a housing professional makes a referral to social work with the consent of the individual to provide assistance in seeking a dementia diagnosis
3. if consent is withheld and major concerns are evidence regarding wellbeing or safety, the housing professional should make an urgent social work referral or adult support & protection referral;
4. the housing professional signposts the individual (with consent) into support services which can provide practical assistance with dementia diagnosis or further information on dementia.

Housing staff should be aware that pathway, referral and signposting processes may differ at a locality level.
### What are the consent requirements surrounding a referral for dementia diagnosis?

Any engagement by a housing professional with a third party agency (health, social work or support agencies) on accessing a dementia diagnosis must always be supported by the consent of the individual.

The importance of seeking permission to share information with health, care and support services is critical. The knowledge requirements of housing professionals include:

- confidentiality and information sharing protocols;
- consent to share mechanisms (at a locality by locality level);
- the consent and process associated with informed consent

#### Practice recommendations

### What data should be collected & shared to support an effective referral for diagnosis?

Housing staff should be aware why understanding the housing context and circumstances of individuals who may be living with early dementia may be useful from a care and support planning perspective.

Where requested (and where consent is in place) the housing professional should be encouraged to share information about the personal and property factors that suggest diagnosis may be considered beneficial.

Often frontline housing staff will have an insight into the capacity and wellbeing of an individual that may be very beneficial to those involved in diagnosis.

#### Practice recommendations

### What does effective communication and collaboration across referral partners look like?

At all times, communication across partners supporting a person living with dementia (diagnosed or undiagnosed) should be supported by the consent of that individual to share information.

Better collaboration to encourage early diagnosis is likely to depend on a deeper acceptance and understanding of the role of the frontline housing professional from health and social work professionals. Housing workers often have the clearest understanding of the personal circumstances and home-life of those living with undiagnosed dementia, which could be offered to support diagnosis and in identifying the range of interventions which could be considered to enable that person to continue to live independently at home.

In collaborating, housing professionals should be encouraged to share objective (factual) information which avoids judgements or stereotypes of the individual. Useful information will focus on what is normal for that person and any changes (noting both personal and property triggers) from those norms.
What should the housing professional expect from a dementia diagnosis referral?

Where a housing professional has been involved in the care and/or support planning process associated with dementia diagnosis, feedback to enable ongoing engagement in the design, delivery and review of interventions to support independent living, should be requested.

Whilst there is no requirement to share the outcome of a dementia diagnosis with housing professionals (and often social landlords won’t know); the individual, their carers, health, care and support services should be encouraged to acknowledge the important role that housing can play in enabling independence in those living with dementia – both in terms of adapting the home environment and through the delivery of support solutions.

4.5. Stage 5: The housing role post diagnosis - how do practitioners enable risk?

Through discussion, participants examined stage 5 in the pathway defining the (i) knowledge requirements; (ii) practice recommendations; and (iii) partnership actions associated with the:

1. role of housing services in offering post diagnostic support and enabling independent living.

Post diagnosis, what (if any) role does housing play in support planning or ongoing case management for a person with dementia?

Housing has a key role to play in the post diagnostic support process, which is often overlooked by link workers in health, social work or dementia services who coordinate support planning under the 5 Pillars model.

Awareness of the important role that housing services can play in enabling independent living within a holistic approach to dementia care should be highlighted:

- at a locality level through integrated joint boards and strategic planning groups;
- at a national level through the third dementia strategy for Scotland; and
- at an operational level across frontline partnerships

Housing plays a key role in adapting the home environment of those living with dementia and should be involved in proactive future planning as needs change. The principles of a housing options approach within an integrated dementia care model should be acknowledged so that preventative action can be planned wherever possible.

Housing also plays a key role in ensuring that the needs of other members of the household (and tenancy) are considered and met. A good example of this relates to ensuring that tenancy rights are protected for those who live in the property if a person with dementia loses capacity.
How should housing organisations link with other support services to enable independent living for those recently diagnosed with dementia?

Housing Contribution Statements should enable progress to be made in establishing the role of housing in an integrated approach to dementia care. Examples of this are emerging, e.g. South Lanarkshire Council has a frontline housing worker located in a hospital to enable a proactive approach to discharge planning.

Housing’s role in an integrated model of dementia care will require to be defined and promoted nationally to enable local partnerships to create operational systems which can realise housing contribution to adapting the home environment, delivering support and enabling social interaction in those living with dementia.

4.6. Key messages: Stages in assisting & supporting dementia diagnosis pathway

Sections 4.1 to 4.5 above have outlined in substantial detail the assessment of the group of professionals on each stage of this pathway. What follows is a brief summary of the key messages:

<table>
<thead>
<tr>
<th>Knowledge Requirements</th>
<th>Practice Recommendations</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Stage 1: Triggers, signals or problems that suggest the need for diagnosis</strong></td>
<td></td>
</tr>
<tr>
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<td>Staff role to signpost customers to services that could support wellbeing and tenancy sustainment (This includes signposting to services that will deliver dementia diagnosis.)</td>
</tr>
<tr>
<td>Staff should be aware of impairment of memory, reasoning and learning, increased stress and reduced capacity Andrews (2013)</td>
<td>Staff should be assured of their ability to make a difference by taking appropriate action to kick start early intervention and identifying options</td>
</tr>
<tr>
<td>Staff should develop a sound awareness of DSCS material on diagnosis</td>
<td>Staff need to be equipped with skills to manage sensitive conversations on dementia diagnosis.</td>
</tr>
<tr>
<td>Knowledge Requirements</td>
<td>Practice Recommendations</td>
</tr>
<tr>
<td>----------------------------------------------------------------------------------------</td>
<td>------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td><strong>Stage 2: Signs &amp; Symptoms that check/confirm diagnosis may be of benefit</strong></td>
<td></td>
</tr>
<tr>
<td>Staff should have a strong awareness of the signs and symptoms of dementia based on DSCS material</td>
<td>Ability to establish if changes have been stimulated by a key life event, e.g. bereavement.</td>
</tr>
<tr>
<td>Staff should have a clear understand of the 3 D's – Delirium, Dementia and Depression</td>
<td>Ability to understand simple, informal interactions to build a picture</td>
</tr>
<tr>
<td></td>
<td>Staff should note that respecting the person’s right to give you information is absolutely paramount</td>
</tr>
<tr>
<td></td>
<td>Staff should understand the simple questions that enable assessment of a person's ability to live safely and independently. These dovetail with proactive tenancy management practice.</td>
</tr>
<tr>
<td></td>
<td>Staff need to understand the pathway for channelling concerns that a person would benefit from dementia diagnosis.</td>
</tr>
<tr>
<td><strong>Stage 3: Engaging &amp; Encouraging Diagnosis: what language to use/what to ask</strong></td>
<td></td>
</tr>
<tr>
<td>Staff should be aware of the acceptable language to use when talking about dementia.</td>
<td>Staff should have an understanding of the key practice points to guide communication on dementia diagnosis, together with the importance of trust to enable successful communications.</td>
</tr>
<tr>
<td>Staff should encourage individuals to make decisions and take action and to enable this through signposting to practical support, care and advocacy</td>
<td>Could be opportunities for engagement afforded by proactive tenancy management leading to a more assertive outreach approach</td>
</tr>
<tr>
<td>Staff should be encouraged to share information on the benefits of regular health screening.</td>
<td>Understanding the adult protection process and pathway.</td>
</tr>
<tr>
<td>Staff need to be clear that diagnosis starts with GP engagement.</td>
<td>Housing staff should signpost into the diagnosis pathway. If referrals are made it must be by attaining the consent of the individual.</td>
</tr>
<tr>
<td></td>
<td>It may be appropriate to engage with carers and family. Staff should have an awareness of the principles of the triangles of care.</td>
</tr>
<tr>
<td></td>
<td>Where it is not possible to engage with family or carers and significant welfare concerns remain, should activate adult protection process.</td>
</tr>
<tr>
<td>Practice Recommendations</td>
<td>Partnership Actions</td>
</tr>
<tr>
<td>--------------------------</td>
<td>---------------------</td>
</tr>
<tr>
<td><strong>Stage 4: Making a referral &amp; how to do this effectively</strong></td>
<td></td>
</tr>
<tr>
<td>Staff should have clarity that their role is to encourage the person to take action themselves. There is no mechanism for housing staff to make referrals for dementia diagnosis</td>
<td>Communication across all partners supporting a person with dementia should be supported by consent. Better collaboration to encourage early diagnosis is likely to depend on a deeper acceptance and understanding of the role of frontline housing professionals from health and social work professionals.</td>
</tr>
<tr>
<td>Staff should be aware of 4 key pathways to diagnosis: Motivate person to make self-referral to GP; Make social work referral with consent; Make adult protection referral without consent; Signposting with consent to support services</td>
<td>Through collaboration, housing professionals should be encouraged to share objective (factual) information which avoids judgements or stereotypes.</td>
</tr>
<tr>
<td>The importance of seeking permission to share information is critical</td>
<td>When housing is involved in the care / support planning process, feedback to enable ongoing engagement in design, delivery and review of interventions to support independent living should be provided.</td>
</tr>
<tr>
<td></td>
<td>PWD and Carers should be encouraged to recognise the important role that housing can play in enabling independence</td>
</tr>
<tr>
<td><strong>Stage 5: The housing role post diagnosis – how do practitioners enable risk</strong></td>
<td></td>
</tr>
<tr>
<td>Those coordinating the 5 Pillars model should not overlook the role of housing in post diagnostic support process</td>
<td></td>
</tr>
<tr>
<td>Housing plays a major role in adapting the environment.</td>
<td></td>
</tr>
<tr>
<td>Housing Options model within an integrated dementia care model should be acknowledged.</td>
<td></td>
</tr>
<tr>
<td>Housing Contribution Statements should enable progress to be made in establishing the role of housing.</td>
<td></td>
</tr>
</tbody>
</table>
4.7. **Session 3  Assisting & supporting diagnosis: what happens in the real world? (Part 1)**

Having explored the ‘ideal world’ scenario in Session 3, this session aims to gain an understanding of perspectives on what would actually happen in the ‘real world’ at the present time should a housing practitioner identify that dementia diagnosis should be enabled. This will be done through examining two case studies and reflecting on the ‘ideal scenario’ mapped out in Session 3.

Participants were split into two groups and each given a Case Study to discuss and examine real life practice issues. Group 1 explored Case Study A and considered, “What is likely to happen in practice in this scenario?”

**Mr. Smith (age 83)**

*He is often seen exiting the block of flats where he lives. In recent weeks I have noticed that he has started to look a little unkempt. Our reception staff also mentioned that his latest visits to the office have been a little confused.*

*I checked his rent account and noticed that he has a shortfall on his rent account of two months. This is unusual, as his account has been consistently clear. I made a couple of visits but he wasn’t at home. I left some cards but he didn’t respond. Eventually when I did get him at home, he invited me in and there certainly seems to be problems.*

*Carrier bags of rubbish are building up in the kitchen and there are lots of unwashed crockery on the worktops. There was also a lot of unopened mail behind the front door. The house was not like this the last time I visited him.*

*As I talked with Mr. Smith about whether he needed some help he seemed to be quite confused and a little defensive. At one point I admired a picture of his grandson, and he told me it was son, however it was a picture which had clearly been taken in the past few years. I’m concerned about Mr. Smith, I think he may have some sort of dementia.*

Group A considered that the reality of what is likely to happen in responding at a practitioner level to Mr Smith are as follows:

<table>
<thead>
<tr>
<th>Where are the knowledge or information gaps?</th>
</tr>
</thead>
<tbody>
<tr>
<td>In terms of identifying gaps in information &amp; knowledge, it is important to decide what to do next &amp; figure out where to channel concerns.</td>
</tr>
<tr>
<td>A housing practitioner may have limited understanding of Mr Smith’s personal life or any changes in it.</td>
</tr>
<tr>
<td>It is important to know how to build confidence and trust. Sensitive dialogue should be used in conversations with Mr Smith.</td>
</tr>
</tbody>
</table>
### Are there systems or processes to enable positive service responses?

It’s very unlikely that appropriate systems or processes will be in place to enable positive service responses.

- Case management and/or case history notes may not be fully available in tenancy management systems to make it easy to identify changes to Mr Smith’s disposition/appearance or service engagement levels.

- It’s also likely that poor joint working processes will preclude the sharing of information, risk assessment or planning across housing, care, health & support agencies.

- Consent needs to be obtained from Mr Smith in order to share potentially useful information across different agencies such as housing, social work, health etc. This is likely to be a barrier as consent to share mechanisms are unlikely to be in place.

### What are the barriers to effective joint working and collaboration?

A lack of clarity on the role of the housing professional in supporting people living with dementia is a barrier. Housing professionals may not recognise encouraging diagnosis as part of their role and not address the issue. Furthermore, it could be difficult for a housing professional to transition from conversations with Mr Smith about tenancy and estate management issues to discussions about his general welfare & health.

Beyond making changes to the home environment of people living with dementia through aids & adaptations, it’s often the case that professionals in health, support & care services don’t recognise the contribution that housing services can make to independent living through the sustainment role they deliver. Housing is often not at the table when care plans are designed and coordinated.

### Where does practice need to be developed?

There needs to be a change in service culture where staff are engaged in activity which prevents crisis (including supporting people living with dementia).

It is important to clearly define the housing role in supporting people living with dementia which includes outlining the professional boundaries between housing, health, care & support providers so that housing professionals are confident in the contribution they can and should make.

### Where does co-ordination need to be strengthened?

Networking & communication across different agencies & services needs to improve.

There needs to be some form of audit or review of referrals & protocols across localities so that clear processes and pathways for supporting people with dementia can be established.
### 4.8. Session 4 Assisting & supporting diagnosis: what happens in the real world? (Part 2)

Having considered that the reality of what Mr Smith is likely to experience in terms of service responses given current practice, Group A then considered:

> “Based on what we’ve learned from Session 3 (the ‘ideal world’ scenario on enabling diagnosis) how do we address barriers, problems and gaps to deliver a more effective outcome for Case Study A (Mr Smith)?”

The key interventions defined to improve front line practice for each group include:

<table>
<thead>
<tr>
<th>Question</th>
<th>Intervention</th>
</tr>
</thead>
<tbody>
<tr>
<td>What are the barriers that need to be overcome to improve service delivery?</td>
<td>There needs to be clear referral pathways that outline contacts and processes for collaboration.</td>
</tr>
<tr>
<td></td>
<td>We need to improve communication processes in terms of feedback and review across partners (including housing) involved in supporting people living with dementia.</td>
</tr>
<tr>
<td></td>
<td>Need to address differences in eligibility criteria across services for care &amp; support which may impact on access routes into practical help. Note: the role of the dementia coordinator in providing post diagnostic support should address many of these issues.</td>
</tr>
<tr>
<td>What are the partnerships that need to be created, improved or developed?</td>
<td>Multi agency networking needs to be developed. Training events would be beneficial in developing understanding but may also strengthen connections between agencies.</td>
</tr>
<tr>
<td></td>
<td>Need to develop case management and conferencing processes, deciding who coordinates delivery, monitoring and review activity.</td>
</tr>
<tr>
<td>What are the training needs required to ensure best practice?</td>
<td>There needs to be training on referral pathways and the role of each services in an integrated approach to dementia care.</td>
</tr>
<tr>
<td></td>
<td>Training/awareness raising on the importance of early diagnosis.</td>
</tr>
<tr>
<td>If we could do 1 thing to improve the customer experience what would it be?</td>
<td>Achieving clarity on the role of housing professional and boundaries to other roles would help improve customer experience.</td>
</tr>
<tr>
<td></td>
<td>Well-coordinated case management processes would also heighten customer experience.</td>
</tr>
<tr>
<td></td>
<td>Some sort of leadership planning review also needs to be implemented.</td>
</tr>
</tbody>
</table>
4.9. Session 5: What needs to happen to move from reality to ideal world?

The final workshop activity was designed to focus on the key interventions and learning points necessary to move from current reality to best practice in assisting and supporting dementia diagnosis. To achieve this, workshop participants were asked to define, discuss and prioritise a range of improvement interventions associated with the following question:

“What are the top 5 interventions, improvements or learning points that would enhance practice in assisting and supporting someone to seek a dementia diagnosis?”

To do this, participants were each given a blank A5 cards, and asked to provide 1 action point that they believe is critical to enhancing practice in supporting and assisting dementia diagnosis. Cards were placed on a pin-board and categorised by common themes. Participants were then given 5 minutes at the pin-board to review the range of action points provided by the group, identifying the interventions they feel have most potential in enhancing practice in assisting and supporting dementia diagnosis. Each participant defined the actions they would prioritise by placing stickers on the ideas which would have most influence in improving practice according the action that would have (i) major and positive influence; and (ii) positive influence.

The bank of improvement actions, prioritised by potential influence and impact is as follows:
<table>
<thead>
<tr>
<th>Action Point</th>
<th>Response Category</th>
<th>Major &amp; Positive Impact</th>
<th>Positive Impact</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dementia awareness training for all housing and housing support staff</td>
<td></td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Ensure housing professionals are properly trained and supported to have the confidence to intervene/raise concerns and to know what the intervention should be.</td>
<td></td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>A housing and dementia toolkit which outlines how to start dementia conversations and outlines key dementia supports within each local area.</td>
<td>Training</td>
<td>5</td>
<td>0</td>
</tr>
<tr>
<td>Training for all levels of staff. Giving consideration that not all signs &amp; symptoms of someone’s behaviour merits a formal diagnosis (of dementia). This is because other causes must be ruled out first.</td>
<td></td>
<td>4</td>
<td>1</td>
</tr>
<tr>
<td>Ensure all housing staff are trained to ‘promoting an excellence informed level’</td>
<td></td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Joint training across all sectors – operational networks.</td>
<td></td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>See housing staff as ‘professionals’ and recognise their skills and competence and what they can contribute to the whole health and wellbeing agenda</td>
<td>Role of Housing Professional</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Better co-operation of staff training, e.g. all staff in housing, whether officers or technical, should be trained as dementia friend or dementia aware or ‘promoting excellence’.</td>
<td></td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>These staff should know about the local referral pathways or how people can go about getting more information and/or diagnosis.</td>
<td></td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Improve communications with partners and IT</td>
<td>Communication</td>
<td>4</td>
<td>1</td>
</tr>
<tr>
<td>Communication and improved understanding of housing role to increase joint working / joint approach across housing health and social care.</td>
<td></td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>There needs to be a greater understanding of people’s changing needs. Professionals in all areas need to work together, sharing information in order to support people in their role and so minimising crisis</td>
<td>Awareness and better knowledge</td>
<td>0</td>
<td>3</td>
</tr>
<tr>
<td>Improve knowledge of dementia, how to appropriately discuss concerns without overstepping boundaries &amp; encourage people to access better support/ diagnosis.</td>
<td></td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>
There were four categories of improvement actions defined by participants relating to:

1. Training (6 improvement actions);
2. The role of the housing professional (2 improvement actions);
3. Communication (2 improvement actions);
4. Awareness & better knowledge (2 improvement actions);

On this basis we can conclude that enhancing training in supporting and assisting dementia diagnosis is a key element of improving practice.

The top 5 action points (in order of priority) defined by participants in workshop 1 were as follows:

1. Produce a housing and dementia toolkit which outlines how to start dementia conversations and key dementia supports within each local area;
2. See housing staff as ‘professionals’ and recognise their skills and competence and what they can contribute to the whole health and wellbeing agenda;
3. Training for all levels of staff, giving consideration that not all signs & symptoms of someone’s behaviour merits a formal diagnosis (of dementia) - other causes must be ruled out first.
4. Communication and improved understanding of housing role to increase joint working / joint approach across housing health and social care; and
5. A greater understanding of people’s changing needs. Professionals in all areas need to work together, sharing information in order to support people in their role and so minimising crisis.