

# ARE WE NEARLY THERE YET?

## Enabling People with Dementia to Remain at Home: A Housing Perspective

### EXECUTIVE SUMMARY

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On behalf of the Dementia and Housing Working Group

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In partnership with:

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## ABOUT THE AUTHOR

Sue Garwood was the Dementia Lead for the Housing LIN (Learning and Improvement Network) for about 10 years up until her retirement at the end of June this year and was responsible for building up the dementia pages on the Housing LIN website. Sue is a passionate advocate of dementia awareness and good practice within the housing sector and recognition of the housing sector contribution amongst health and social care professionals. She has been an active member of the Dementia and Housing Working group, Dementia Action Alliance and Housing and Dementia Research Consortium and has made a significant contribution to a number of other national forums and consultations.

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## ENABLING PEOPLE WITH DEMENTIA TO REMAIN AT HOME: A HOUSING PERSPECTIVE

# EXECUTIVE SUMMARY

## INTRODUCTION

A key aim of the [\*2020 Dementia Challenge\*](#)<sup>1</sup> is to “enable people living with dementia to be supported to live independently in their own homes for as long as they are comfortable and safe to do so” (5.76 of the DH Implementation Plan). This report on a scoping project undertaken on behalf of the [\*Dementia and Housing Working Group \(DHWG\)\*](#) assesses progress towards achieving this goal, the factors which either facilitate or impede its achievement, and the actual and potential contribution of the housing sector. The report provides a platform from which more detailed work to make specific recommendations can be done at a later date.

The term “housing sector” is used broadly to include housing associations, local authority housing departments, home improvement agencies, private sector housing providers, trade bodies, developers, and architect and surveyor companies. The sector develops and delivers a wide range of accommodation models and services, some specifically for people with dementia including: specialist housing; aids, adaptations and home improvements; repairs and handypersons services; information and advice services; housing management and housing-related support services; services to support hospital discharge; and various activities based in their housing schemes. Examples of these are included in this report.

Members of the Dementia and Housing Working Group (DHWG) and other professionals, mainly from the housing sector shared their knowledge and expertise through workshops and survey responses. Four Alzheimer’s Society Service User Review Panels also identified the factors they considered most important in enabling them to live independently. The process sought to pull together a picture of what was happening ‘on the ground’ across a range of domains which have the capacity to facilitate or impede the ability of those living with dementia to remain at home including, but not limited to, housing-related ones. Progress and good practice examples were identified as well as issues and impediments.

## **FINDINGS – SECTION I – HOUSING ISSUES**

Discussion amongst the project advisory group following the consultation identified five areas for priority attention. Those suggested all have in common a fundamental underpinning role, have a dementia-specific component, and have the potential for influence by the housing sector.

### **ACCESS TO BROAD-RANGING INFORMATION, ADVICE AND ADVOCACY**

1. This was chosen because without conspicuously accessible, unbiased information and advice about the options available – and in this particular context housing-related options which people affected by dementia may not know exist – informed choices cannot be made.
2. There are many good sources of information and advice on-line, by phone and face-to-face both nationally and locally. Some provide dementia-specific information, others more general but inclusive information. Some are provided by the housing sector and many focus on certain types of services or products.
3. However, despite the abundance of information available, people may not know how to access it, it may not be bespoke to diverse communities, and it is unclear how well co-ordinated and comprehensive the different information and advice services are.
4. The picture seems patchy and fragmented. Professionals may lack knowledge of available service options, particularly housing-related ones. It may not be enough to provide information; people with dementia may need information carefully timed and repeated, and may need support or advocacy to navigate the system rather than simple signposting.
5. More work is needed to assess the accessibility, quality, content and inter-connectedness of information and advice sources to ensure that everyone living with dementia and their carers can readily gain access and make informed choices, even if they do not have contact with mainstream services.

### **INTEGRATED WORKING ACROSS SECTORS, DISCIPLINES, SERVICES AND POLICIES**

1. This subject was chosen because it is so fundamental to cost-effective, co-ordinated support, yet, despite the efforts made by many to achieve recognition of the important role of housing options and professionals, working in partnership with health and social care professionals remains a major challenge to the housing sector.
2. Individuals and their families and carers want different services to work together to enable cohesive, integrated and personalised assessment and support.
3. There are good examples included in the report of effective joint working across sectors. However, housing professionals often feel excluded from collaborative working at an individual level, their knowledge of an individual ignored, and their concerns dismissed. Service commissioners may not consider housing-related options when commissioning services for people with dementia.
4. Work needs to continue at all levels and across sectors to ensure housing options and professionals are integral to enabling people with dementia to remain in their own homes.

## **A WELL-INFORMED, AWARE AND SKILLED HOUSING WORKFORCE**

1. This is fundamental to the way in which people with dementia are related to and helped, and most people with dementia live in ordinary housing stock whether in the social or private sectors.
2. As outlined in [\*MAKING A START: Dementia – Skilling the General Needs Housing Workforce\*](#), dementia training needs to be tailored to the housing workforce. Some housing providers have developed bespoke training programmes while others erroneously believe that a Dementia Friends session constitutes training and is sufficient, if they recognise the need for dementia-awareness at all.
3. More work is needed to get the message across to housing sector employers.
4. More bespoke training courses need to be developed and accredited, the respective roles of the Chartered Institute of Housing and Skills for care need to be clarified and communicated to the sector.

## **DEMENTIA DESIGN – OF HOUSING, AIDS, ADAPTATIONS AND TECHNOLOGY**

1. This area was selected because good design underpins good products
2. Dementia-design principles are increasingly applied to specialist housing schemes, but not beyond. Some housing providers apply these when refurbishing schemes. Nevertheless, while the principles may be understood, there appears to be less clarity about their implementation in practice. More work is needed to ascertain where good dementia design overlaps with design for other needs and where it is distinctive, and this information widely disseminated.
3. A myth persists that all dementia design is costly, and poor marketing and awareness of products results in some “dementia products” carrying a cost premium unjustifiably.
4. There is some designing of aids, adaptations and technology devices specifically for people with dementia, but more are needed, particularly those that are co-designed with people with dementia and then evaluated to ensure user-friendliness and effectiveness.

## **DATA COLLECTION AND RESEARCH**

1. This was chosen as a topic because not enough is known about what is happening ‘on the ground’ and what ‘works well’ in the context of housing and dementia; evidence should be a key driver for change and improvements.
2. Research that is specific to housing and dementia is limited. The [Housing and Dementia Research Consortium](#) exists to try and remedy this. Obtaining funding for this is really difficult.
3. For each domain there is a range of possible steps to improve the application and implementation of what is known to be good practice. In addition, for most there is also a knowledge or evidence gap which needs to be filled by gathering of basic data and undertaking research to generate evidence.

## OTHER HOUSING-SPECIFIC AREAS

The picture across other housing-specific topics was also considered: housing supply; aids, adaptations, repairs and improvement; technology; and dementia-friendly housing organisations.

1. There is a growing supply of specialist housing for older people and those with dementia but not enough to meet the need, nor enough ordinary housing that is easily adaptable and/or suitable for people with dementia and other disabilities and impairments.
2. Questions remain about what is the right amount of different sorts of housing, and which building and design standards should apply to which housing types.
3. Aids, adaptations and assistive technology can make an important contribution to enabling people with dementia to live well and safely at home. Home Improvement Agencies do a good job, but more is needed and more emphasis needs to be paid in the Disabled Facilities Grant to compensating for cognitive rather than sensory impairments and physical disabilities.
4. A number of housing providers have developed dementia strategies and are working towards becoming dementia-friendly, but they appear to be in the minority.
5. The development of a [dementia-friendly housing charter](#) should assist housing organisations to become dementia-friendly provided they recognise the importance and value of doing so.

## FINDINGS – SECTION 2 – THE BIGGER PICTURE

In addition to the housing-specific topic areas covered in Section 1, a number of more general and widely applicable factors (domains) were identified, based on the knowledge and experience of those undertaking the project.

Some of the areas prioritised for attention from a housing sector perspective have wider importance and more general relevance but are not covered again in this section. These include:

- a) Access to wide-ranging information, advice and advocacy
- b) Integrated working, shaped around the person with dementia and their informal carers – across sectors, disciplines, services and policies
- c) Data collection and research

In addition to the three above, a number of other themes cut across many of the domains, on balance exerting a negative influence at present:

### I. FUNDING – ACCESS TO ADEQUATE FUNDING TO MEET NEED, ENABLE QUALITY AND INVEST IN PREVENTION

Local authority budget cuts, cuts in welfare spending, and insufficient funding to meet demographic changes have a significant impact. They result in a range of shortages and quality issues across most domains, including: the availability of good quality formal services (e.g. adult social care, home care services, health services, housing management and housing related support) and informal services (e.g. befriending and peer support); the provision of awareness raising and training in dementia and related topics within entire workforce; the supply of suitable homes, aids and adaptations; and funding for research.

## 2. INCLUSION AND ABSENCE OF STIGMA – AN INFORMED PUBLIC AND DEMENTIA-FRIENDLY COMMUNITIES

People with dementia need to feel they are equal citizens with equal rights and a contribution to make. While there are some excellent initiatives such as [DEEP](#) (Dementia Engagement and Empowerment Project) and [Dementia Words Matter](#) which appear to be successfully promoting inclusion of people with dementia and fighting stigma, ageism is still rife. Apocalyptic narratives around dementia remain, as well as stigmatising of those experiencing it, often compounded by misconceptions or prejudice e.g. towards people in the LGBT and South Asian communities. The media have a fundamental role in perpetuating attitudes or positively re-shaping them.

## 3. WELL-INFORMED, AWARE AND SKILLED WORKFORCE ACROSS ALL SECTORS AND INDUSTRIES

Many in the workforce across the board lack the knowledge and skills to: work effectively with people living with dementia; signpost to a full range of support options including housing-related ones; and effectively implement the law. This topic was seen as a priority generally as well as specifically in relation to the housing sector.

4. The remaining domains considered include: **relationships and informal support** which are highly valued and to which the housing sector can and does make a positive contribution; the availability of **practical help and formal support services** which are seen as fundamentally important but severely challenged; **policy and regulation** including the Mental Capacity and Care Acts which, while broadly positive and progressive, are inconsistently implemented; and the importance of **meaningful activity**.

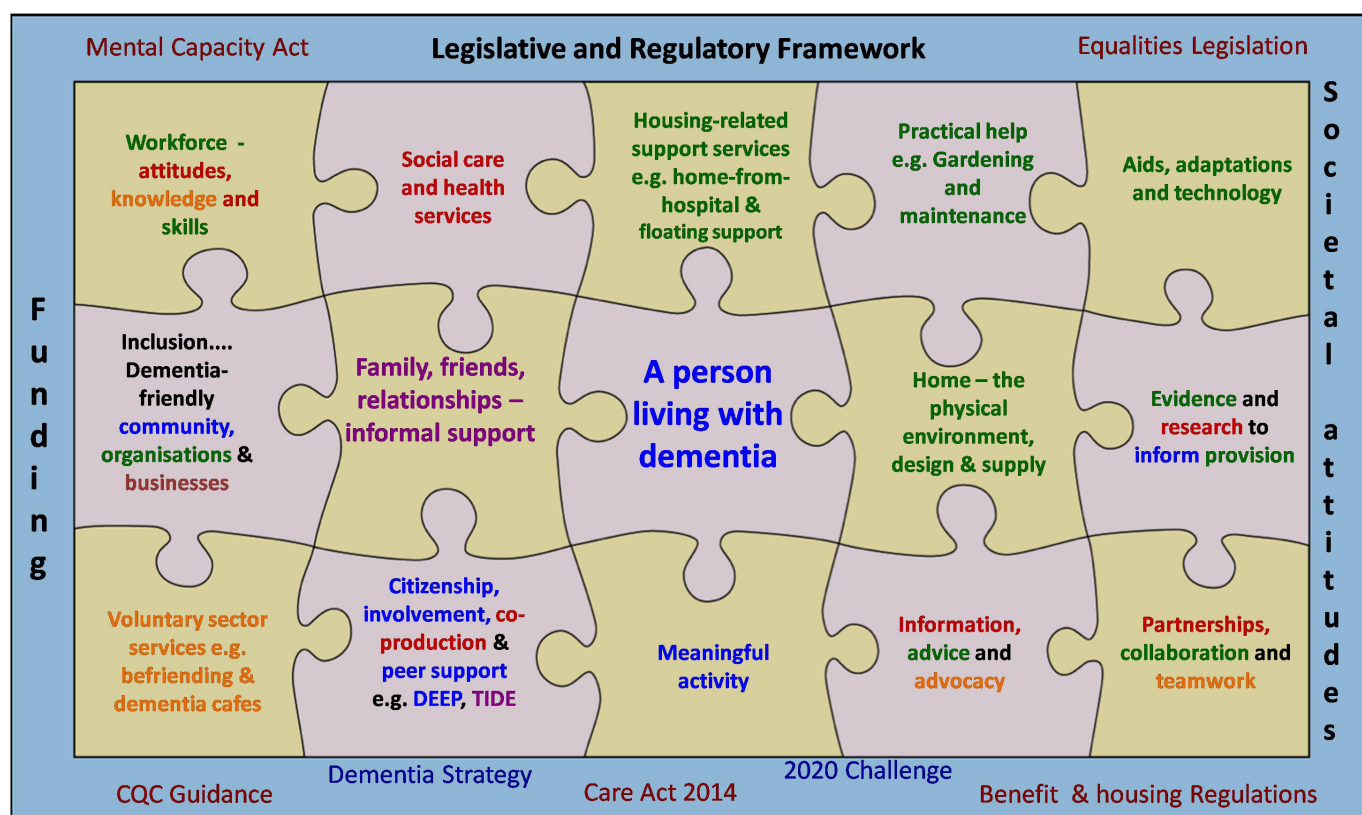
## CONCLUSIONS

1. Across all domains there are examples of good practice and pockets of innovation but the picture is patchy and fragmented, and there is not consistent implementation across the country.
2. Within each of the five housing priority areas, suggestions have been made as to how the situation could be improved, but do not go so far as to make specific recommendations at this stage. The report provides a platform for further work to be done on the priority areas identified, which could be taken forward by the UK Dementia Envoy to achieve the aims of the 2020 Dementia Challenge.
3. The housing sector could do more than it is already doing if:
  - a) More effective working together with health and social care could be achieved at individual and wider planning and commissioning levels;
  - b) More of the workforce was trained in dementia, in line with their role and degree of contact with people who may have or develop dementia;
  - c) Housing organisations worked towards becoming more dementia-friendly by signing up to commitments in the dementia-friendly housing charter;
  - d) Funding cuts were not in place resulting in a paring back of staffing levels.
4. For people with dementia, knowing where to go for information, advice and advocacy is fundamental, yet knowing where to start and obtaining personalised advice is challenging. This applies particularly to people not in contact with mainstream services (e.g. self-funders), marginalised groups and those who are digitally excluded.



5. More data and research is needed across all domains to gain a more complete picture and build evidence of what works. In the meantime, better use could and should be made of existing guidance, tools and evidence by commissioners, planners, architects, policy makers and housing organisations. This applies, for example, to dementia-design, service commissioning, and skilling the workforce.
6. Innovation and design of new products such as technology devices, aids and adaptations should involve people with dementia from the outset and their user-friendliness and usefulness to people with cognitive impairments properly evaluated.
7. Although identified separately, the different domains do not stand alone. The presence or absence of positive practice in one exerts an effect on another and many are inter-dependent. The picture – how things work together – may vary from locality to locality, but for people with dementia to be able to remain living well at home within their local communities as full and equal citizens, all the jigsaw pieces need to fit together – or, put another way – all the factors that have an influence need not only to be positive and effective in their own right, but should also dovetail with one another.
8. The housing sector makes a considerable contribution to enabling people with dementia to remain living comfortably and safely in their own homes, but it is only one piece in the jigsaw. The following aspirational jigsaw illustrates this point and suggests where, as a society, we need to get to.

## PERSON-CENTRED COMMUNITY SUPPORT



## THE DESTINATION – AN INCLUSIVE COMMUNITY



## ABOUT THE DEMENTIA AND HOUSING WORKING GROUP

The Dementia and Housing Working Group (DHWG) focuses specifically on housing and dementia with a view to promoting the role of the housing sector in enabling people with dementia to live independently in a suitable home environment in accordance with their needs and aspirations.

The DHWG comprises housing providers, professionals and trade bodies working alongside the Alzheimer's Society and researchers. A number of government bodies also attend meetings: Department of Communities and Local Government; Department of Health; Homes and Communities Agency; NHS England; and Public Health England. We aim to:

- Forge links and partnerships across health, social care and housing and encourage positive relationships, to develop a coordinated approach to supporting people with dementia
- Increase awareness and understanding of dementia across housing sector
- Encourage and assist the housing sector to become as dementia-friendly as possible in the way they operate, and to contribute to making the communities within which they work dementia-friendly
- Improve awareness and understanding amongst statutory and voluntary sector health and social care professionals of the relevance and importance of housing and related services in enabling people with dementia, their families and communities to live well
- Encourage integrated care and support pathways that include housing options, housing sector staff and housing-related services for people with dementia through all stages from prevention to end-of-life care

The DHWG is currently chaired by Homeless Link. For more information on the DHWG see:

<https://www.housinglin.org.uk/housing-networks/dementia-and-housing-working-group>

## ABOUT THE HOUSING LEARNING AND IMPROVEMENT NETWORK

We are a sophisticated network bringing together over 40,000 housing, health and social care professionals in England and Wales to exemplify innovative housing solutions for an ageing population.

Recognised by government and industry as a leading 'knowledge hub' on specialist housing, our online and regional networked activities:

- connect people, ideas and resources to inform and improve the range of housing choices that enable older and disabled people to live independently
- provide intelligence on latest funding, research, policy and practice developments, and
- raise the profile of specialist housing with developers, commissioners and providers to plan, design and deliver aspirational housing for an ageing population

For more information housing and dementia, visit the Housing LIN's Focus on Dementia web-pages at:

[www.housinglin.org.uk/Dementia](http://www.housinglin.org.uk/Dementia)

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