



# ARE WE NEARLY THERE YET?

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

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On behalf of the Dementia and Housing Working Group

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In partnership with:







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### **ARE WE NEARLY THERE YET?**

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

# INTRODUCTION

#### THE REPORT

A key aim of the <u>2020 Dementia Challenge</u><sup>2</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 <u>Dementia and Housing Working Group</u> (<u>DHWG</u>) assesses progress towards achieving this goal, and the actual and potential contribution of the housing sector.

It is based on findings from a survey and workshop which drew upon the knowledge and expertise of members of the Dementia and Housing Working Group and other associated professionals, as well as four Alzheimer's Society Service User review Panels.

The report sets out the current picture as perceived by the participants including areas where progress has been made and the challenges and issues that remain.

While the project began by consulting on the bigger picture and then narrowing the focus by selecting a small number of priority housing areas through discussion, the report begins with a detailed look at the suggested priority areas, moves on to other housing-related topics in less detail, and ends with a headline account of the bigger picture.

The findings are divided into two main parts:

- 1. The first covers housing-specific topics, entitled "Housing Issues". This is split in two:
  - a) firstly, the five areas suggested as priorities for future attention, in which statements about the general state of play are followed by the challenges and ideas for improving the situation;
  - b) secondly, other housing-specific topics in which a more general round-up is given.
- 2. The second part, entitled "The Bigger Picture" provides a very brief resumé of the current state of play across a much broader and ross-cutting range of domains. These provide the wider context within which the housing sector is a small but significant part, and with which it needs to dovetail.

Both parts include relevant examples and case studies.

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#### **PROJECT RATIONALE**

We know from recent data that:

- 850,000 people in the UK are living with dementia<sup>3</sup>
- Age is a risk factor and the population is ageing<sup>4</sup>
- Around 70% have another medical condition or disability<sup>5</sup>
- Two-thirds of those with dementia live in their own homes, mostly in non-specialist housing<sup>6</sup>
- The vast majority (85%) of those with a diagnosis of dementia would prefer to remain in their own homes<sup>7</sup>
- People with a diagnosis of dementia spent 4.2 million nights in hospital in 2015-16, up from 3.5 million in 2009-10; many will have been admitted to hospital from their own homes but do not return there.<sup>8</sup>

The purpose of this project was to consider some of the factors at play in enabling people with dementia to live well in their own<sup>(i)</sup> homes and explore the role of housing and associated services in achieving this aim.

In addition to a number of housing providers with a strong commitment to becoming dementia-friendly, <u>membership</u> of the Dementia and Housing Working Group comprises a range of trade and industry bodies, each with its own broad membership, giving the Group extensive reach.

Rather than undertaking a formal research study, the rationale behind the methodology was that the combined knowledge and expertise of members of the DHWG and their networks would bring a unique perspective to the question of enabling people with dementia and their partners to remain at home. The survey and a full description of the methodology is included in the Appendices (p.62).

This approach cannot give a complete and comprehensive overview of what is happening across the country since the picture is fragmented and will vary from one locality to another, but it can identify key themes.

A wide range of factors can help people with dementia and their partners to remain living well and independently in the home of their choice. Alternatively those same elements can be barriers. Some relate to the built environment, some to the wider social environment. We sought to identify areas and examples of good practice, as well as some of the issues. The housing sector may have considerable control or influence over some factors and relatively little over others.

By housing sector, we include all organisations that design, build, develop or manage housing as well as those involved in aids, adaptations, repairs and improvements to mainstream (ordinary) or sheltered housing. We include not only the buildings where people live (place) but also the services these organisations provide, the processes within them, and the workforce (people) they employ or contract with. The following documents explain this in more detail: <u>Dementia-friendly Housing Charter</u><sup>9</sup>, <u>Dementia and Housing Assessment Tool for Local Commissioning</u><sup>10</sup> and <u>Making a Start: Dementia – Skilling the General Needs Housing Workforce</u>.<sup>11</sup>

Importantly, even within the narrow definition of housing as the place where people live, it means far more than bricks and mortar. It is our home. As identified in work undertaken by the Life Story Network, <u>Beyond the Front Door</u><sup>12</sup>, it is a place you put your stamp on; it holds memories and can provide a sense of connectedness and belonging; it forms part of your sense of identity. FINDINGS – SECTION 1

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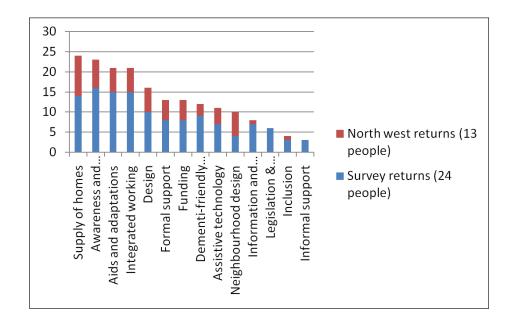
<sup>(</sup>i) "Own homes" includes ordinary housing as well as specialist housing such as sheltered or extra care schemes. The term covers social and private sector housing as well as a range of tenures; example outright ownership, leasehold properties, shared ownership and properties for rent. It does not include residential or nursing homes.

# FINDINGS - SECTION 1: HOUSING ISSUES

# 1. SUGGESTED PRIORITIES FOR HOUSING-RELATED FOLLOW-UP

Thirty-seven people responded in the survey to the following question:

Which are the top five areas you think should be priorities **for action by the housing sector**, either because that is where the sector can make the most difference or because you regard that area as particularly in need of attention?



Domain	Number	%
Housing supply	24	65
Awareness & training	23	62
Aids & adaptations	21	58
Integrated working	21	58
Design	16	43

The results of the survey were combined with workshop discussions and feedback from the SURPs to develop a list of five priority housing-related areas for more detailed analysis and further work. These differ slightly from the graph above. Following feedback from other stakeholders in the discussion groups, neither supply of suitable homes nor aids and adaptations, for example, have been included in the priority list despite their position in response to the survey question, although design is relevant to both and has been included. The reasoning behind this was that the five areas selected were considered to be, on reflection, more central and relevant to this project because they all have three things in common: a fundamental underpinning role in supporting – or failing to support – people with dementia to live independently; a definite dementia-specific component; and the housing sector can play a key role in influencing them.

- A) Information and advice 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.
- B) Integrated working 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.
- C) Skilling the housing workforce was chosen because it is fundamental to the way in which people with dementia are related to and helped.
- D) Design of homes, adaptations and technology was selected because good design underpins good products and there is still uncertainty about how best to implement dementia design principles, there is insufficient inclusion of people with dementia in designing new products, and often they are not tested and evaluated for their usefulness and effectiveness.
- E) Data collection and research 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.

A further section (F) will briefly cover the other housing-specific domains, before moving on to the broader non-housing domains in the second half of the report.

# FINDINGS - SECTION 1: HOUSING ISSUES 1. SUGGESTED PRIORITIES FOR HOUSING RELATED FOLLOW-UP

# A. ACCESS TO BROAD-RANGING INFORMATION, ADVICE AND ADVOCACY

Is there good access to information, advice and advocacy both at a national and local level that enable people with dementia and their carers to make informed choices about where they live and what form their support should take? Are they accessible to people from diverse communities? Who provides these services?

#### **CURRENT CONTEXT**

- 1. This issue is fundamental. Without access to information and advice about their rights and options, people with dementia and their families are not able to make informed choices. The Care Act 2014 requires local authorities to ensure that these are available, although there is not a duty on them to provide these services themselves.
- 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. There is a range of dementia-specific sources of information, some of which include housing-related options:
  - a) The <u>AT Dementia</u> website provides information on assistive technology for people with dementia; it give advice on communication, safety, leisure and prompting/reminder devices, and where to find them;
  - b) <u>Dementia Connect</u> is Alzheimer's Society's comprehensive services directory for people affected by dementia in England, Wales and Northern Ireland. People access the information by entering their postcode;
  - c) The <u>Alzheimer's Society</u> offers information in a range of other ways including a helpline, on-line "Talking Point", website, leaflets etc;
  - d) The <u>Dementia Law Clinic</u> (see case study in box below);

- e) The <u>Unforgettable website</u> is targeted at people living with dementia and offers a range of products, services and advice. Products include aids and technological devices, for example reminders and locators;
- f) <u>Ask Sara</u> provided by the Disabled Living Foundation (DLF) provides information and advice to help people with disabilities to live independently. It is not dementia- specific but has a link to AT Dementia;
- g) <u>AlzProducts</u> describes itself as the one-stop dementia shop containing a large range of dementia aids and equipment for those with cognitive loss;
- h) SCIE have a <u>web-page</u> devoted to the home environment.

# MAKING SPACE – DEMENTIA LAW CLINIC AT LEGAL ADVICE CENTRE AT MANCHESTER UNIVERSITY

Making Space is a registered charity which provides a range of services for older people, carers, and people with dementia, mental health issues or a learning disability. Their service offer includes Supported Housing.

The Dementia Law Clinic is a brand new service that has been set up in partnership with the University of Manchester, and is just the second clinic in the country to offer free legal support to dementia carers.

The clinic will provide advice on the many complex issues people can face when caring for someone with dementia, including home disputes and powers of attorney.

One-to-one consultations via Skype will be available to discuss personal circumstances, and receive legal advice from professionals.

The service can provide advice on many different legal issues surrounding dementia, including:

- Advance Decisions (previously known as Advance Directives) to refuse treatment
- Community Care Assessments
- Continuing Healthcare
- Court of Protection
- Deprivation of Liberty Safeguards (DoLS)
- Disputes of Best Interests for those who lack capacity
- Disputes of Mental Capacity
- Legal Power of Attorney (LPA)
- Provision of care (in relation to care homes)
- Trust and Inheritance probate

The service runs various "hot spots" across the country where legal, Admiral nursing and communication appointments are on offer.

For more information, visit: <a href="https://www.makingspace.co.uk/our-services/dementia-law-clinic/">www.makingspace.co.uk/our-services/dementia-law-clinic/</a>

- 4. EAC <u>FirstStop</u> provides inclusive advice and information on housing, care and finances. It also provides links to sources of local information. The sort of information covered by each local source varies.
- 5. <u>Elderly Accommodation Counsel</u> has a comprehensive database on various forms of accommodation for older people as well as a range of home services.
- 6. Many home improvement agencies (HIAs) nationally and locally provide information and advice, for example <u>Leeds Directory</u> is managed by Care and Repair Leeds. Preston Care and Repair have a specific <u>Live Well with Dementia service</u>. Information on local HIAS can be found at <u>Foundations</u>, the national body for home improvement agencies.
- 7. Age UKs nationally and locally are a good source of information.

# AGE UK WARWICKSHIRE FIRST STOP AND GP CARE NAVIGATOR SERVICES

<u>Age UK Warwickshire</u> (AUKW) is a registered charity working throughout the county of Warwickshire, employing 240 staff supported by 460 Volunteers, providing a wide range of services to 30,000 plus older people and their carers every year.

In 2015 the charity became part of a national Dept for Communities and Local Government (DCLG) pilot initiative – the Elderly Accommodation Council's FirstStop programme – designed to help to meet this need for integrated, impartial information, advice and practical help around housing, care and related finance in later life.

At around the same time AUKW was starting a ground breaking GP Care Navigator Pilot in South Warwickshire which was pro-actively visiting older people, identified by their GP as being at higher risk, in order to undertake a holistic assessment and offer interventions to reduce risk.

Clearly, housing was an important part of that intervention offer and so the two initiatives were connected and complementary. Both programmes were independently evaluated and significant estimated savings identified.

Although not targeted specifically at people with dementia, they were included. One case study in the housing-related <u>evaluation</u><sup>13</sup> describes how a couple lived in a small hamlet. The location of the housing became unsuitable when the husband's dementia made it unsafe for him to drive. The couple were given information, advice and support to move to more suitable housing, resulting in a much improved situation as well as estimated cost savings.

For more information on this initiative see: <a href="http://careandrepair-england.org.uk/wp-content/uploads/2017/05/AgeUk-W-Evaluation-report-Final.pdf">http://careandrepair-england.org.uk/wp-content/uploads/2017/05/AgeUk-W-Evaluation-report-Final.pdf</a>

- 8. Some good local or organisation-specific examples include:
  - The housing and care provider Belong employs an Admiral Nurse to provide information advice and support;
  - b) The housing provider Guinness Trust employs a Dementia Advisor and offers in-depth financial assessment and advice;

- c) In Essex, the Citizens Advice Bureau has developed an inter-agency referral website making it simple to refer people and ensure that people don't get lost to the system;
- d) <u>Knowsley Independent Living Centre</u> has a large showroom with a range of equipment, aids and adaptations to help people live more independently at home. There is also an independent living centre in Bristol and BRE are planning to develop something similar in Watford, Hertfordshire;
- e) The <u>Information NOW Newcastle info website</u> provides information and advice on a range of topics targeted at older people.

#### HAMPSHIRE DEMENTIA ADVISOR SERVICE

The Dementia Advisor service is currently available to anyone who lives in Hampshire and who has received a positive diagnosis of dementia or mild cognitive impairment. This service aims to support and enable people with dementia to live as well as possible with their condition and independently for as long as possible. It also aims to support the carers of people with dementia to help them carry on caring and look after their own wellbeing.

This service is jointly commissioned by health and social care organisations and forms part of a holistic approach to care and support provision.

#### The service aims to:

- Provide timely and tailored information, signposting and support for people with dementia or mild cognitive impairment and their carers.
- Take a long term conditions approach and focus on the well being and empowerment of the person living with dementia and their carers, helping them to accept their diagnosis and live well with their condition, building resilience and independence.
- Facilitate access to, and understanding of, local community, health and social care support available.
- Provide support with long term, and contingency planning.
- Provide a point of continuity throughout a person's journey with dementia arranging for information to be shared (with the patient permission) when appropriate to offer a seamless journey from pre diagnosis to living well with dementia.
- Promote a greater understanding amongst the general public as well as people living with dementia and their carers, social care and health professionals and community organisations of:
  - dementia and how it is experienced
  - the Mental Capacity Act and legal protections
  - finance and benefits
  - coping strategies
  - mainstream and specific opportunities in the community (e.g. lunch club or dementia/ memory café)
- Provide carers with information as well as emotional support and tailored strategies to remain resilient over time

It is accessible to people from diverse communities although focus work is currently undertaken as part of contract monitoring to understand why take up is lower than expected. The DAS does put people in contact with peer support groups and will signpost to home improvement agencies, Telecare and any home safety schemes (Cold spot scheme, fire safety etc). They work primarily with people in their own homes and the service stops when people are admitted to residential care. In Gosport, on the first Monday of the month the Dementia Adviser Drop in service is provided in an sheltered housing scheme for people living there and also the local community to meet with the DA and get advice and information.

For more information, visit:

https://www.hants.gov.uk/socialcareandhealth/adultsocialcare/olderpeople/dementia

#### **ISSUES AND CHALLENGES**

- 1. Despite these examples of information and advice resources, there are some key issues and challenges. Despite all the many linkages and attempts to co-ordinate, the picture across the country appears to be patchy and fragmented.
- 2. From a general perspective
  - a) There is still a tendency towards compartmentalisation. For example the local AS Dementiaconnect websites appear not to have a housing category.
  - b) There may also be a lack of bespoke information for people from diverse communities e.g. BME communities.
- 3. The picture is patchy geographically too.
  - a) EAC FirstStop has local partners (many are HIAs or local Age UK branches) that provide information, but what they cover varies and these appear not to be country-wide.
  - b) Some local authority service directories are broadly inclusive while others may restrict the information they provide to certain categories, e.g. their own directly provided services.
- 4. From the public's perspective
  - a) Systems are complex and the amount of information can be overwhelming.
  - b) People often don't know where to start, particularly if, as self-funders or members of hard-toreach groups, they do not have contact with mainstream services, which at the start of their 'journey' they often do not have. Much seems to depend on the diligence and thoroughness of the service they first make contact with, with 'memory clinics' often being the best resourced – if they get that far.
  - c) Feedback suggests that GPs are often the least well-informed.
  - d) Access and knowing where to start is even more difficult for those who do not have a support network.
  - e) Carers often don't know their rights as identified in Carers' Trust research Care Act one year on. 14
  - f) Information is sparse about what is available in the way of adaptations and improvements to the home, in particular those which may be helpful to people with dementia.

- g) When diagnosed, people may be given written information and then left to get on with it. That may not be the point at which they need the information so this may need to be repeated or reinforced at a later date.
- h) In addition, some people with dementia are unable to use information or signposting. Indeed their cognitive impairment may mean they forget that it has been given to them. They may need direct referral, support or advocacy to navigate the system.
- i) Many older people and those living with dementia may not have internet access or the skills to search the net, and may lack the capacity to learn these skills resulting in digital exclusion.
- j) People need information in different ways, at different times one size does not fit all.
- k) People may have misconceptions about sheltered and extra care housing, seeing them as nursing homes, so may be reluctant to consider them.

#### 5. Health, social care and housing professionals

- a) In terms of person to person information, it depends on the experience and knowledge of the advisor.
- b) Social workers' knowledge of housing-related services is variable, health sector staff even more so. Ignorance of, and misconceptions about housing options amongst many health and social care professionals can result in discharge from hospital to care home unnecessarily, or discharge to sheltered schemes without adequate support provision.
- c) Anecdotal evidence suggests that Care Act provision for advocacy for those without support, who have difficulty making decisions, is not applied consistently.
- d) Housing providers' own material is not always clear about what they are offering.

#### 6. Cultural issues

- a) There is often low uptake from BME communities this may be because they fear being stigmatised or they may be culturally resistant to seeking advice. Language barriers and fear of engaging with authority may also play a part.<sup>15</sup>
- b) Fear of prejudice may deter people from LGBT communities from seeking help and advice tailored to their needs.<sup>16</sup>
- 7. There is a debate as to whether holistic and comprehensive information should be available from a single, well known source or whether it needs to be available at all the places people frequent, e.g. GP surgeries, sheltered housing schemes and post offices. Probably both are needed with effective linkages and signposting between them.
- 8. Good information and advice needs to include universal provision available to all, including those living with dementia, as well as dementia-specific information, because:
  - a) Information, advice and advocacy is needed not only for those with a diagnosis of dementia, but also for those pre-diagnosis, some of whom may have memory or other challenges
  - b) Even if someone is diagnosed as having dementia, they may be deterred by anything marketed as dementia-friendly or bespoke

#### 9. Funding issues

- a) Although the Care Act puts duty on LAs to ensure information and advice are available, funding was not specifically earmarked for this and local authority budgets are squeezed.
- 10. The term "dementia-friendly" may be bandied about without agreement as to its meaning in relation to specific features or services, or indeed depth of understanding. What it means for a shop assistant or librarian, is likely to be insufficient for a GP receptionist, or indeed the GPs themselves.

#### ADDRESSING THESE CHALLENGES - WHAT NEEDS TO BE DONE?

- 1. Further work is needed to ascertain the interconnections and degree of co-ordination between organisations providing information, advice etc and where there is scope for improvement. They may be more connected than we realise.
- 2. Further co-ordination and collaboration between the different advice agencies, with input from people with dementia and their carers could be explored.
- 3. Would it be desirable or feasible to work towards all agencies covering all categories as comprehensively as possible? Or perhaps co-ordinating rather than replicating material that covers the same topics? Or agreeing a standard signposting process?
- 4. Information services perhaps require greater diversity in order to transcend language and cultural barriers in the system, and information needs to be provided in a range of formats.
- 5. Raise awareness and locate basic information where people with dementia may go to provide a starting point, e.g. GP surgeries, churches, post offices.
- 6. More initiatives using a range of media to publicise and improve understanding amongst the public (bearing in mind a significant self-funder population) of:
  - a) Where to access information, advice and advocacy;
  - b) What different housing options can and can't offer.
- 7. More initiatives bringing together people from diverse communities with professionals to engender greater mutual understanding, enabling information, advice and services to be shaped accordingly.
- 8. More initiatives to raise awareness and understanding amongst health and social care professionals of:
  - a) What different housing options can and can't offer
  - b) The importance of GPs referring on for specialist assessment, advice and support, e.g. to memory clinic or local HIA.
- 9. Include discussion about housing options during Care Act support planning and post-diagnostic support programmes, alongside making a will, Lasting Power of Attorney and financial planning.

#### 10. Roll out valued services

- a) More Admiral Nurses or other dementia specialists needed to provide information, advice and support throughout the journey;
- b) More independent living centres;
- c) Greater use of HIAs as information sources.

#### 11. Housing sector

- a) Housing professionals could play a part in helping people with dementia to understand the options they have, as well as to support and signpost them, provided that they themselves have the necessary information and time. Funding cuts make this more challenging. It also has implications for awareness raising and training of their own staff.
- b) Local housing authorities could provide information on all local housing-related options so that people do not need to approach housing associations separately.

- c) Housing providers should produce clearer information about what they offer in different types of accommodation.
- 12. The local authority duty under the Care Act to ensure information is provided should be properly resourced.
- 13. The term "dementia-friendly" as it applies to different organisations and services needs to be defined and a common assurance/accreditation process put in place, possibly with a rating system.

## FINDINGS - SECTION 1: HOUSING ISSUES

## 1. SUGGESTED PRIORITIES FOR HOUSING RELATED FOLLOW-UP

# B. INTEGRATED WORKING ACROSS SECTORS, DISCIPLINES, SERVICES AND POLICIES, SHAPED AROUND THE PERSON WITH DEMENTIA AND THEIR CARERS

Is there effective integrated working "on the ground" across sectors, in particular between housing, health and social care?

#### **CURRENT CONTEXT**

- 1. This is a matter of central importance, both because individuals and their families and carers want different services to work together for the individual to enable cohesive, integrated and personalised assessment and support, and because provision is likely to be more cost-effective if the potential of all available resources are maximised to the full, and duplication avoided.
- 2. The Care Act promotes a holistic and integrated approach and the Better Care Fund which includes the Disabled Facilities Grant is aimed at improving integration across sectors, including housing.
- 3. There is growing recognition of the relevance of housing and related services but progress is very slow despite efforts of some in the housing sector and there's a long way to go.

#### **DEMENTIA DWELLING GRANT, WORCESTERSHIRE**

Worcestershire is the first county in the UK to trial a new grant scheme which will pay for adaptations to homes using the Better Care Fund, making them safer and more convenient for local residents living with dementia. The trial was due to begin in April 2017 and will be formally evaluated by the University of Worcester's Association for Dementia Studies (ADS).

Grants of up to £750 will be available for eligible people living with dementia. The grant will not be means-tested, but will be based on the assessment of each individual's needs. It aims to help reduce feelings of confusion and anxiety, thereby enabling them to remain at home for longer.

For more information, visit:

http://www.ageuk.org.uk/herefordshireandworcestershire/support-services/ddg/

- 4. Whether and how different organisations and professionals work together varies from place to place. Typically it depends on particular individuals. There is not a consistent picture across the country and more information is needed to gain a full picture.
- 5. There are good examples across the country of jointly funded projects delivered by the housing sector that either directly target people with dementia or include them, as well as professionals from different sectors working together, with the contribution of the housing sector being recognised and included.
  - a) Accord Housing works together with Age UK Walsall, St Giles Hospice, Pathways for Life and others on a range of dementia-focused services including extra care, dementia cafés, day services and Pathways for Life dementia advisors<sup>17</sup> (see Meredith Beeching presentation at <a href="https://www.housinglin.org.uk/Events/West-Midlands-Region-Housing-LIN-Meeting-Birmingham/">https://www.housinglin.org.uk/Events/West-Midlands-Region-Housing-LIN-Meeting-Birmingham/</a>)
  - b) The Bromley Dementia Hub Service is a post diagnosis support service comprising four elements: dementia advice and navigation service; community development and support service; carer training service; and skills training and support in Extra Care Housing.
  - c) The Hampshire Dementia Advisor service (see separate case study p.12)

#### **ONE HOUSING REABLEMENT**

Roseberry Mansions Reablement Service is a ten unit service which provides intensive short term support and therapies to enable people who have been hospitalised to return home or to other appropriate long term accommodation.

The main aims of the service are to:

- improve the quality of people's lives by enabling and re-skilling them to be able to return home or to other appropriate accommodation in a sustainable way
- facilitate earlier hospital discharge and avoid unnecessary or repetitive hospital admissions

- prevent or delay the need for long term residential or nursing care placements
- deliver significant NHS and adult social care savings.

The Roseberry Mansions Reablement Service is run by One Housing, a not-for-profit organisation providing homes and care to over 5000 people in London and the surrounding counties.

The dedicated onsite multi-disciplinary healthcare team (MDT) is commissioned by Camden Adult Social Care and delivered by Central and North West London NHS Foundation Trust. Working together with One Housing's care and support workers, the MDT consists of:

- social services
- occupational therapist
- physiotherapists
- speech therapists
- district nurse input

The service appears to have delivered significant savings to the NHS and adult social care.

Irene, an 85 year old woman with dementia benefitted from this service in that it enabled her to have a trial at Roseberry Mansions before moving permanently to Extra Care housing. See case study.<sup>18</sup>

# OLDHAM BME ELDERS HOUSING AND HEALTH PROMOTION PROJECT

This case study focuses on a project which was undertaken and jointly funded and delivered between 2014 and 2016 by a range of Oldham partners – the Council, Housing & Care 21, Aksa (part of New Charter Group) and Oldham Housing Investment Partnership (OHIP) and Clinical Commissioning Group. The project included but was not limited to a dementia focus. It involved working with Pakistani and Bangladeshi communities living in Oldham to understand their current housing needs and future housing aspirations, and explored the potential to facilitate healthy lifestyle behaviour change within these communities. Two outreach support workers who shared the background and communities of the people with whom they were engaging were employed by Housing & Care 21. Their role was to engage with the Bangladeshi and Pakistani communities to achieve these outcomes. The workers were bilingual and awareness of the service was raised through using of the BME media and leaflets distributed in Asian areas, schools, businesses and mosques.

Approximately 200 people attended early intervention sessions held in mosques and specific community/leisure centres. These had a range of focuses including Dementia Friends, signposting for early help and awareness of housing options. There were also community days at local housing association schemes and Dementia Friends sessions delivered in a range

of settings including housing schemes and schools. As a result, 113 Dementia Friends have been made in Bangladeshi and Pakistani communities, all of whom have committed to actions which improve the lives of people living with dementia.

At the end of the project in 2016, one outcome identified was that a culturally sensitive dementia-awareness package was needed which utilized the experience of Bangladeshi and Pakistani people. This is being taken forward with other groups in Oldham. In addition, the project has developed a pioneering pathway to communicate with local mosques and involve them in the local health and housing agendas. Access was gained to the mosques through the wives of the Imams and Mosque Committee members. A grassroots approach proved successful in communicating with established groups, raising awareness of healthy lifestyle behaviour among BME communities. And finally, awareness was raised of sheltered schemes and extra care schemes, leading to increased interest in these as housing options.

For further information, read the Housing LIN case study<sup>19</sup> at: <a href="https://www.housinglin.org.uk/">https://www.housinglin.org.uk/</a> Topics/type/BME-Elders-Housing-and-Health-Promotion-Project/

#### **SELWOOD HOUSING DEMENTIA PILOT**

As a housing association and social enterprise, Selwood Housing is working to improve homes and communities. It has 5,500 homes across Wiltshire and Somerset, including affordable housing, sheltered housing, care homes and Independent living centres. Selwood housing also offers 'floating support,' which helps people to live independently in their home as well as community alarm and telecare services called Selwood Lifeline.

In February 2009, Selwood Housing was commissioned by Wiltshire Council to provide a telecare pilot for people living in West Wiltshire and Devizes area, who have dementia. The pilot aimed to establish how well telecare could help to support people with dementia to live independently in their own home, and assess the impact on carers.

The intended outcomes of the pilot were to:

- Prevent the number of re-admissions to hospital
- Delay the need for admission to a care home
- Promote independence
- Enable customers to stay at home longer
- Provide support to the carers of customers
- Form part of care packages, reducing the staffing hours and cost

A working group consisting of telecare providers, Wiltshire Council, Wiltshire Medical Service, Care Connect and representatives from Health agreed a set of key performance indicators including installations, equipment costs, call outs, value for money and length of time the telecare package was in place to identify and measure outcomes. Statistics and qualitative evidence from customer and carer feedback was collated by the relevant parties.

#### Reported outcomes:

- Hospital and care admissions were reduced/avoided/delayed
- Carers felt supported and reassured and were able to have respite for short periods as they felt the customer was safe with the technology in place
- Customers were happier with a telecare installation compared to additional care staff as the equipment was less intrusive to their lives
- Customers were able to stay at home for longer which was their primary aim
- Medication could be better managed with the support of the equipment and monitoring centre
- The risks to the customer from fire, flood, temperature extremes, walking about, bogus callers and other factors were significantly reduced through the equipment installed

#### **MRS GREEN**

Mrs Green is a 96 year old woman with a diagnosis of Alzheimer's disease who lives alone. She has a very supportive family who visit every day, and she also receives a care package. Mrs Green was referred to the telecare dementia pilot by her occupational therapist as she was having cooking accidents regularly, and had burnt her legs by sitting too close to her gas fire. Mrs Green would also leave her home to go shopping alone and then become disorientated. The family spent a considerable amount of time looking for Mrs Green and they received several calls from neighbours concerned about her safety.

#### THE SOLUTION

After completing a joint assessment with both the family and the Occupational Therapist the telecare team suggested that:

- A Lifeline unit and pendant should be installed to enable Mrs Green to easily call for help
- A smoke detector and carbon monoxide detector be provided to raise an alarm at the monitoring centre if Mrs Green gets into difficulty cooking a meal
- A temperature extremes sensor be fitted in the sitting room to monitor for sudden bursts of heat from the gas fire which would hopefully prevent any further burns to Mrs Green's legs
- A property exit sensor should be installed that would inform the monitoring centre when Mrs Green had left her home and not returned within the pre-determined time. The monitoring centre would then contact the family so they could respond.

#### THE OUTCOME

Mrs Green's family are less anxious as they know that if there is a problem, the monitoring centre will contact them, and that they can spend more quality time with Mrs Green. Mrs Green is happier as she feels safer in her home and knows if she is worried she can speak to the monitoring centre at any time.

For more information on Selwood Lifeline, visit: https://selwoodlifeline.co.uk/tag/assist/

#### **WORKING TOGETHER AT BROOKSIDE HOUSING WITH CARE**

This is a good example of a housing provider working closely with health and social care services.

Brookside is a mixed tenure housing with care scheme in Ormskirk, West Lancashire, where people living with dementia are dispersed across the scheme to aid integration. Your Housing Group owns the whole building, while the land is let under a long term lease from the council. The scheme was designed following dementia-friendly principles by Pozzoni LLP.

In addition to 111 properties, a bistro open to the local community, and a range of communal facilities typically available in such a development, it includes a number of more specialist facilities:

- the Merebrook Day Centre for people with dementia which is run by Lancashire County Council. The residents integrate with the day centre visitors in the dementia-friendly garden, helping with potting, planting etc;
- offices which house the Community Older Adult Mental Health Team and the Memory Assessment Service, comprising community mental health nurses and a psychologist, consultant psychiatrist, social workers and occupation therapists;
- offices for Age UK & West Lancashire Alzheimer's Society whose dementia advisors are based there.

There are also a number of treatment rooms and a memory assessment room. The scheme acts as a local hub for the community. Any NHS community staff member can hot desk.

Your Housing Group provides a facilities management service. In addition the NHS funds an administrative post, a key function of which is to provide a reception service and signpost people to the appropriate service.

Memory assessment clinics take place throughout the week and health professionals run consultations and clinics at the scheme. These serve residents of the scheme as needed, as well as people from the local community. In addition, neuro-psychology have a clinic once a week, there are outpatient clinics for the mental health team, Age UK runs a foot clinic, the Health Trust runs a falls clinic and the Alzheimer's Society runs a weekly "singing for the brain" session. The HICA Group provides a 24 hour waking care service at the scheme.

The Your Housing Scheme Manager works closely with staff from HICA, the Mental Health Team and the Alzheimer's Society. Relationships are good. As well as having a weekly meeting with HICA staff, the scheme manager can talk to the Alzheimer's Society dementia advisors or members of the Mental Health Team if she has concerns about a resident.

HICA's "Wellness Nurse" comes in once a week. She runs a drop-in service for residents at which she takes their blood pressure, attends to weight & dietary needs, keeping records on weight gain & losses, as well as visiting residents in their properties if there are specific concerns, and liaises with family members and other services as necessary. HICA also employs an activities co-ordinator who facilitates a range of activities for residents, including a reminiscence group.

For more information, read the Housing LIN case study at:

https://www.housinglin.org.uk/Topics/type/Taking-extra-care-with-dementia-friendly-design-Brookside-Retirement-Living-Village-Lancashire/<sup>20</sup>

#### **ISSUES AND CHALLENGES**

Despite the good examples of joint working itemised above, the following detailed case study illustrates some common themes in the relationship between housing providers and local adult social care (ASC) teams.

# MR E - CHALLENGES OF GETTING ADULT SOCIAL CARE TO ENGAGE

Mr E was 90 years old; he had spent his working life in the Royal Marines and had been happily married up until the late 80s when his wife died. He had one daughter who lived abroad and had a Court of Protection order allowing his solicitor to deal with all his financial matters. Mr E lived in a first floor flat with no lift managed by a Registered Social Landlord (RSL).

In January 2016, a dementia advisor working for the RSL was emailed about Mr E by his Housing Officer.

The Housing Officer reported that she had been receiving regular complaints from Mr E's neighbours for the past 6 months and had been trying, unsuccessfully, to engage with the local Older Persons' Mental Health Team (OPMHT) and social services (ASC) about Mr E. She had also visited Mr E to discuss the complaints but there had been no change in his behaviour and she was in a position where she should issue Mr E with a notice seeking possession as this was the next stage of the anti-social behaviour process. She was uncomfortable about doing this as she had recently been informed that Mr E had dementia, and although it was just a warning letter she was not sure that it would be reasonable or have the desired effect — which was to encourage Mr E to improve his behaviour.

The Housing Officer and Dementia Advisor met to discuss the situation. It transpired that Mr E had been "wandering", throwing rubbish over the balcony, banging late at night, and his behaviour had also changed to the point that he was being verbally aggressive at times to people he knew well, and had previously got along very well with. The Scheme Manager also reported that he had been pulling his safety cord and had been seen arguing with himself in his bedroom mirror.

The Dementia Advisor advised the Housing Officer that the situation was different from an anti-social behaviour case. Instead of issuing a sanction, there was a need to look at the support that could be offered to Mr E. They also agreed to meet with the other residents so the Housing Officer could address their expectations; in the past residents had been advised that if they kept records for a prolonged period of time then tenancy action would be taken against Mr E.

The Dementia Advisor agreed to attend a coffee morning to discuss the dementia project as a way of explaining a little more about how dementia can affect some people. It was clear that Mr E could not be talked about specifically, but it could be explained to residents that where a person's behaviour is as a result of a health condition, the response may need to be slightly different.

The Housing Officer had previously arranged three multi-agency meetings that had not been attended by any of the external services. Mr E's neighbours had real fears that one morning

they would open their door and find him dead from a fall or the cold weather. He had become very unsteady on his feet and there had been reports that he had almost fallen on multiple occasions.

The Housing Officer scheduled another meeting as Mr E's "wandering" had progressed and there were concerns for his welfare. The local Older Persons' Mental Health Team, Adult Social Care (ASC), Mr E's solicitor, his home care team and the Dementia Advisor were all invited to attend. The meeting was poorly attended; only the OPMHT, the care provider and the housing provider were represented. ASC declined to attend and also did not appoint an advocate despite the substantial difficulty Mr E was having understanding, retaining and weighing up the information, and the solicitor only had responsibility for Mr E's finances. Doctor's reports had been called for and were available to be reviewed.

A plan was put in place to increase Mr E's home care and the OPMHT was asked to carry out a review of his needs. When this had been done previously, it was felt that he was capable of continuing to live independently, although it was accepted that his condition was declining. Cards were posted through all doors at the scheme explaining to residents how to report a welfare concern directly to the local authority, on the understanding that the more reports the authority received, the more quickly they would be likely to respond.

The RSL engaged with the police, who also had safeguarding concerns which they reported to the local authority. Mr E continued to decline and the RSL continued to struggle to engage with external services whilst working hard to keep the other residents satisfied. They were advised of further incidents and Mr E did, as had been predicted, have a minor fall.

Mr E began to have continence issues but at the same time a report came back from ASC advising that he had capacity to make decisions regarding his housing and had no continence issues.

Shortly after this Mr E placed a number of items down his toilet causing a blockage which led to a major flood. There was extensive damage to the flat below and to his flat. The RSL was notified and took the decision to arrange a short decant for Mr E whilst the damage was put right. Whilst this would be disorientating for Mr E it would not have been safe for him to be at home during the work and would have been detrimental to his overall well-being.

The housing provider finally managed to engage with ASC and Mr E was found a suitable placement in a local specialist dementia care home. A further reassessment of needs was requested. This took place but the findings were vague. The housing provider was advised that should Mr E settle then he may be able to remain permanently at the home. They were also advised to carry out their own assessment to assess whether Mr had the capacity to live safely back in his home.

After three weeks Mr E was finally assessed by ASC as not having the capacity to live independently and it was agreed to be in his best interests to remain in the home and give up his tenancy. This was a decision taken by ASC, OPMHT and Mr E's solicitor. The housing provider was not included in this best interests decision-making process. Mr E's tenancy was terminated and his belongings were cleared and moved over to his new home.

The key issue here is that had Mr E not caused this flood he would potentially still be in this situation. The RSL had been considering applying to the Court of Protection for an order to be

put in place for making decisions regarding his welfare. This would have been both costly and taken some time.

More than four meetings were scheduled and were not attended by ASC. Many calls and emails went unanswered. At the point of reporting safeguarding concerns some residents were told that theirs couldn't be logged as they didn't know his date of birth. Some were promised a call back to take more information and never received one.

The failure of agencies to work together is a real concern and puts people like Mr E at risk every day. Regardless of their housing status, people with dementia should receive the support they need to help them make decisions about their long-term welfare.

- 1. It is common for housing sector professionals to be left out of the loop in individual cases, and housing-related solutions may not be considered when commissioning/developing new services.
  - a) Housing is often not seen as an equal partner either strategically or at operational level.
  - b) Housing sector professionals are often not taken seriously when they raise concerns, e.g. when someone with dementia is in breach of tenancy and needs more support than the housing provider can deliver.
  - c) Housing support staff are not regarded as credible professionals so are not included in discharge planning – often the information they send into hospital with residents is ignored. Nor are they kept informed.
  - d) As mentioned previously, there is often poor understanding amongst health and social care professionals of what different forms of supported housing do and do not offer so that:
    - People are discharged back to sheltered housing without adequate social care support or even an assessment – because false assumptions are made;
    - ii. People with dementia are directed towards extra care housing even if it is unable to meet their needs.
  - e) There is a lack of understanding amongst health and social care professionals of the housing sector generally and the contribution the housing sector could make; not necessarily only in the form of accommodation but also a range of other services e.g. floating support, activities, home from hospital or support on discharge schemes (See <u>Collaborative HIAs report</u><sup>21</sup> which outlines what HIAs currently offer and their potential).
  - f) Housing barely gets a mention in many of the NHS Sustainability and Transformation Plans (STPs)<sup>(ii)</sup>, let alone housing and dementia together.
  - g) There is also often limited knowledge of local resources and options beyond those in their own (health or social care) sectors.
- 2. There is a tendency still to regard integrated working as applying only to health and social care. The housing sector is often seen as an add-on rather than integral to the process and if considered at all tends to be an afterthought.

<sup>(</sup>ii) <u>STPs</u> are five-year plans, running from October 2016 to March 2021, covering all aspects of NHS spending in England.

- 3. Other complications include the fact that people may have co-morbidities requiring complex responses and that healthcare is free at the point of delivery, while most of the needs generated by dementia seem to be seen as requiring social care. The logic to this is unclear since dementia is also a disease and long-term condition.
- 4. Effective integration is too dependent on individuals... commitment and leadership is needed from the top of organisations to embed an ethos and strategy of joint working.
- 5. The complexity of the housing sector itself creates a challenge so much energy is needed to try and integrate health and social care that little is left to extend to engaging with the heterogeneous housing sector.
- 6. There are specific issues in relation to the implementation of the Mental Capacity Act and deprivation of liberty, with inadequate capacity assessments, and an unwillingness to take housing professionals' concerns seriously and provide support to the sector in relation to the termination of occupancy agreements where a person with dementia lacks the mental capacity to agree, and there is no Lasting Power of Attorney in place.

#### ADDRESSING THESE CHALLENGES - WHAT NEEDS TO BE DONE?

1. Housing associations and home improvement agencies already do some good work for people with dementia and could do more if they and their services were included more in service commissioning and support planning.

#### 2. Raising awareness and training

- Education and awareness-raising is needed within health and social care sectors about the housing sector and what it offers – whilst recognising this is complicated because, for example, even within the same housing typology, schemes vary, so this measure needs to be taken locally as well as nationally.
- b) Housing organisations in a given locality could work together to improve the understanding amongst their local health and social care services of the potential of the housing sector offer and what the housing related options in that area do and do not provide.
- c) Housing should be more vocal about the work it does and how it aligns with other local partners' priorities. However, there needs to be an open door to have these discussions, and a willingness on the part of all partners to work together more flexibly to arrive at solutions.
- d) It would help if a housing module was embedded in social work training.
- e) It would also help if housing were a standard section in all care and discharge assessments.
- f) Housing staff need the necessary training and support to have confidence in making their case to health and social care professionals, e.g. in relation to safeguarding, mental capacity and deprivation of liberty.

#### 3. Funding

- a) The ramping up of the DFG within the Better Care Fund provides a good opportunity for local authorities, CCGs and Public Health professionals to create better targeted, more effective and innovative services.
- b) Pooled budgets could reduce tensions around different pots of money.

#### 4. Strategically

- a) The inter-sector health and housing <u>Memorandum of Understanding</u> to support joint action on improving health through the home could be extended to include dementia-focused activities and examples.
- b) Housing should be considered more in Sustainability and Transformation Plans.
- c) Tools such as <u>Dementia and housing: An assessment tool for local commissioning</u><sup>22</sup> should be used by those responsible for market shaping and commissioning for the local population.

#### 5. Operationally

- a) Community dementia teams should consider including a housing professional
- b) Consideration could be given to more co-location of staff from different sectors e.g. GPs, primary health and/or mental health professionals based in housing schemes (See Brookside example p.22).
- c) Better use could be made of housing stock and communal facilities, e.g. voids for re-ablement services, meeting rooms.
- d) More schemes such as the Orbit care and Repair Home from hospital service could be developed (see p.53).

## FINDINGS - SECTION 1: HOUSING ISSUES

## 1. SUGGESTED PRIORITIES FOR HOUSING RELATED FOLLOW-UP

# C. A WELL-INFORMED, AWARE AND SKILLED HOUSING WORKFORCE

Everybody, including employees, Board members, contractors and volunteers working for an organisation whose customers may have or develop dementia need awareness, knowledge and skills appropriate to their particular role. What are housing organisations doing to ensure this wide range of personnel have the necessary knowledge and skills to work sensitively and effectively with people living with dementia?

#### **CURRENT CONTEXT**

- 1. <u>MAKING A START: Dementia Skilling the General Needs Housing Workforce</u><sup>23</sup> was published on behalf of the DHWG in May 2014. Although targeted at general needs housing providers, it applies equally to private sector and specialist housing providers, as well as home improvement agencies.
  - a) A key recommendation, corroborated by <u>research</u> undertaken by Professor Claire Surr<sup>24</sup>, is that in order to be meaningful, dementia training needs to be tailored to the organisation, setting and particular roles of the workforce.
  - b) The report segments staff into different categories based on their likely level of contact with people who have or may develop dementia
  - c) It suggests different levels of training based on staff category
  - d) It suggests topics that need to be covered
- 2. Some housing providers have developed their own bespoke training programmes, sometimes in partnership with training organisations, and include the entire workforce and contractors, but they are not typical. For many, "Dementia Friends" sessions for front-line staff are as far as it goes. It is important that these sessions are recognised as intended as awareness raising, not training.

#### ABBEYFIELD DEMENTIA TRAINING PROGRAMME

Abbeyfield has developed a flexible dementia training programme for its staff. The range of dementia learning options is based on the guidance within the *Dementia Core Skills Education* and *Training Framework* commissioned by the Department of Health in 2015. Options combine a mix of free and paid-for resources and distance, e-learning and face-to-face sessions at three different levels:

#### LEVEL 1

**Awareness** which everyone should have. This is targeted at all staff including those not providing direct care and support such as catering, maintenance and admin staff. Learning options include taking part in a Dementia Friends session and/or Redcrier Silverbox distance learning "Caring for People with dementia"

#### LEVEL 2

**Basic skills** which are relevant to all staff in settings where people with dementia are likely to live. This is targeted at all care and support staff and front-line housing staff. Options included in this category are the tools available on the SCIE dementia gateway, the University of Worcester *Stand By Me* e-learning course, Virtual Dementia tour, Abbeyfield Dementia Awareness training provided by external suppliers, a Care Certificate for care staff and QCF levels 2/3 and a range of dementia videos.

#### **LEVEL 3**

**Leadership level**, targeted at a range of senior staff and managers. Options for this level include subject-specific webinars and learning, Abbeyfield's own Advanced Dementia Awareness training and CQF levels 4/5. Leaders of dementia services will be offered training to develop dementia care coaches within housing and care services.

- 3. Housing organisations that also provide care services are more likely to recognise the need to be dementia-friendly and provide training, though it is not clear the extent to which this will be bespoke to housing rather than care roles where these are distinct.
- 4. The Dementia and Housing Working Group is now represented by the Housing LIN as well as Homeless Link on the Dementia Workforce Advisory Group (DWAG) led by Health Education England and Skills for Care. The Housing LIN is also represented on a 2020 Challenge "Meaningful Care" task and finish group: "Supporting the development of a skilled workforce in dementia care", chaired by Skills for care. The purpose of the involvement is to ensure inclusion of the housing workforce in initiatives to improve dementia-related skills and facilitate mutual benefit and understanding.
- 5. Discussions with the Chartered Institute of Housing (CIH) have been instigated by the Housing LIN Dementia Lead about the respective roles of the CIH and Skills for Care in relation to accreditation and supply of materials and training for housing sector staff who do not provide care.

#### **ISSUES AND CHALLENGES**

1. A lack of knowledge and skills leads to difficulty in supporting independence and causes distress amongst staff, the person with dementia and carers

- 2. Within the housing sector, dementia training may have a low priority, particularly in the context of budget cuts which also make it more difficult to release staff to attend training.
- 3. There may be a misconception that it is only front-line staff who need to understand dementia.
- 4. The housing sector workforce is often still excluded from initiatives aimed at improving dementia understanding and skills. Continual prompting seems necessary to gain recognition and inclusion of the housing workforce.
- 5. The respective roles of Skills for Care, the Chartered Institute of Housing and other professional and accrediting bodies in relation to the housing workforce are unclear.
- 6. Although improving, there is still not much in the way of accredited, bespoke dementia training for the housing sector available.
- 7. Housing staff may struggle to understand the health and social care system and may be confused by the use of jargon and acronyms. They need knowledge and skills to challenge health or social care professionals.
- 8. Similarly health and social care professionals need a better understanding of the housing sector and its terminology.

#### ADDRESSING THESE CHALLENGES – WHAT NEEDS TO BE DONE?

- 1. The DHWG, Housing LIN and other industry bodies should continue to raise awareness in the housing sector of the relevance of dementia, and the importance of skilling the workforce to the appropriate level for their roles.
- 2. Engaging in forums that bring together housing, health and social care could improve housing professionals' understanding of the local health and social care systems and language.
- 3. Training providers should be encouraged to develop bespoke training and qualifications using the <u>Dementia Core Skills Education and Training Framework</u><sup>25</sup> where pertinent, but ensuring they are tailored to housing roles and settings so that the content is meaningful to participants and also addresses sector differences (e.g. deprivation of liberty authorisation arrangements) and particular housing issues (e.g. capacity and occupancy agreements, or behaviour issues and anti-social behaviour as seen in the example of Mr E p 32). Use of the DHWG report and resource pack <u>Making</u> a Start<sup>26</sup> can assist in this.
- 4. CIH and other relevant bodies should accredit bespoke training and clarify respective roles regarding dementia qualifications and resources for housing staff who are not registered to provide care.
- 5. Housing organisations that deliver services to people who may have dementia should make dementia awareness sessions a mandatory part of induction for all staff and Board members.
- 6. There should be more "experience workshops" between professionals and people with dementia and carers to share understanding of what living with dementia and other conditions is really like.
- 7. Training is not enough. Learning needs to be reinforced in different ways, and staff supported to work well with people with dementia. Housing organisations should be encouraged to recognise that skilling their workforce in dementia is a good start but not sufficient. They should work towards becoming dementia-friendly organisations whose ethos, policies, procedures and practices throughout the organisation are dementia friendly by signing up to commitments in the <u>Dementia-friendly Housing Charter</u>.<sup>27</sup>

## FINDINGS - SECTION 1: HOUSING ISSUES

## 1. SUGGESTED PRIORITIES FOR HOUSING RELATED FOLLOW-UP

# D. DEMENTIA DESIGN - OF HOUSING AIDS, ADAPTATIONS AND TECHNOLOGY

There are some generally accepted principles about designing homes for people with dementia, for example, layout, lighting, way-finding, clarity of function, decoration, and flooring. Is the knowledge about designing homes for people with dementia being applied? And is this in specialist housing, ordinary housing or both? And what is the position concerning the design of aids, adaptations and technology for people with dementia?

#### **CURRENT CONTEXT**

1. Amongst large 'housing with care' developers in social and voluntary sectors, dementia design principles appear to be increasingly recognised and applied to newly built specialist housing, although this may be superficial in some cases where cost is used as a reason for not doing so.

# JAMES TERRY COURT, ROYAL MASONIC BENEVOLENT INSTITUTION

PRP architects are often asked to provide small dedicated dementia care 'clusters' within their proposals. James Terry Court in Croydon (76 En-Suite Care Bedrooms, including 16 no. dementia care) is an example. The Royal Masonic Benevolent Institution (RMBI) scheme combines both new build and refurbishment. Rooms are spacious; they have specially designed en suite showers and discretely built-in overhead tracking throughout to provide future flexibility for high dependency nursing care. The whole scheme is dementia friendly, not only the specific dementia accommodation.



For more information visit: <a href="https://www.rmbi.org.uk/james-terry-court-croydon">https://www.rmbi.org.uk/james-terry-court-croydon</a>

# HARE HILL HOUSING WITH CARE SCHEME<sup>28</sup>, ROCHDALE BOROUGHWIDE HOUSING

Drawing on <u>HAPPI principles</u>, Hare Hill has been designed to maximise residents' feeling of safety and security whilst also creating delineated areas of life and social activity. The dementia friendly scheme is supported by attractive communal facilities which are open to the public, in combination with other areas which are exclusive to the scheme residents.

A number of features were included to help those with dementia:

- The use of 'memory boxes' and kitchen windows allows residents to personalise their own apartment entrance using personal trinkets or objects, and greatly helps them to orientate themselves and encourages interaction.
- Different colour themes are used on each floor with complementing décor, soft furnishings and artwork.
- Within the apartments the spaces have been laid out so that the toilet is visible from the bed.
- There is a circular route within the secure garden space.
- The single point of access from the outside, which is through the communal space, allows residents and the bistro staff to keep an eye out for residents.

For more information, read the Housing LIN case study at:

https://www.housinglin.org.uk/Topics/type/Location-location-location-Hare-Hill-Littleborough-in-Rochdale-The-perfect-location-for-extra-care/

#### **BELONG VILLAGES**

<u>Belong villages</u> combine assisted living apartments with registered residential care households specifically designed for people with dementia.

Pozzoni architects designed the Belong households to ensure clear lines-of-sight across openplan spaces. This assists orientation and helps to make sure that residents can easily find their way to familiar surroundings wherever they may be. Individualised visual cues can compensate for memory problems.

The open nature of the households means that carers can monitor the wellbeing of residents in unobtrusive ways, and every personal room comes equipped with smart technology to detect falls or unexpected movements without invading privacy.

The extra-wide doorways and bathrooms are fully accessible to wheelchair users, with easy-to-open doors and colour contrast furnishings to enhance perceptibility. From the wet-room shower design to the easy-to-reach plug and light sockets, it has been designed to allow greater freedom and independence.

Communal facilities are open to the public, providing places to meet and creating a community hub, whilst design and technology ensures security is not compromised.

More information about Belong Villages at: <a href="http://www.belong.org.uk/">http://www.belong.org.uk/</a>

#### **BEECHES MANOR EXTRA CARE SCHEME, HOUSING & CARE 21**

Housing & Care 21 had the vision to translate the Green House® model of dementia care home living into a model which supports people in a cluster of one bedroomed flats rather than en-suite bedrooms. Quattro Design Architects translated this vision of care into a built form and Wokingham Borough Council embraced the model.

At Beeches Manor two clusters each of nine one bedroom flats are arranged on the ground floor around garden courtyards with the 'home zone' as the focus at the head of the court and easily visible from all flat front doors for best way-finding.

Each cluster has its own front door in a prominent location internally and externally with separate identity to aid recognition. A domestic style hall opens directly into the farmhouse kitchen with a focal point hearth, living area and themed den. The prominence of kitchen and hearth enhances a sense of homeliness and familiarity. The assisted bathroom and its associated WC are more discretely located, as is the door providing access between the cluster and the shared ancillary part of the building.

Residents leave their cluster by the front door and re-enter the shared part of the building to use the laundry and activity room. However their living room has direct patio access to the woodland garden.

For more information, read the Housing LIN case study<sup>29</sup> at: <a href="https://www.housinglin.org.uk/Topics/type/Beeches-Manor-Wokingham-a-template-for-Dementia-Housing-with-Care/">https://www.housinglin.org.uk/Topics/type/Beeches-Manor-Wokingham-a-template-for-Dementia-Housing-with-Care/</a>

- 2. A number of organisations have taken the initiative to train technical staff in dementia design:
  - a) Pozzoni architects have held dementia design sessions with building contractor staff including the site manager so they understand why the building is designed the way it is.
  - b) Waltham Forest Housing Association has provided workshops and training sessions for architects in partnership with the local DAA and also provided training sessions for Dulux and contractors which have paid dividends on recently developed schemes.
  - c) The Heads of Development at Abbeyfield have training from Stirling University and the Head of Dementia Innovation at Abbeyfield looks at all the plans for development.

- 3. There is less application of dementia-design principles or even HAPPI or Lifetime Home Standards in new mainstream and ordinary housing where turnover is expected, first time buyers and families are the target purchasers, and there are few incentives to apply dementia design principles.
- 4. There is a lot of good material about dementia design available including guides and tools for assessing how dementia-friendly a building is. Most of these can be found on the <a href="Housing LIN Dementia design website page">Housing LIN Dementia design website page</a>. Not all dementia-friendly design features need to cost more.

#### **CO-PRODUCED DEMENTIA DESIGN GUIDE**

People living with dementia, health and social care professionals, academia and business came together to develop and test out innovative solutions in real life settings to produce two volumes: Volume 1: Design for dementia – A guide<sup>30</sup> and Volume 2: Design for Dementia – Research projects.<sup>31</sup>

The co-authors worked with Mersey Care NHS Foundation Trust and Liverpool John Moores University (who both part funded and sponsored the publication) and the Dementia Action Alliance and The Liverpool Service User Reference Forum (SURF) who participated in action research and co-design. The work is part of a long running and ongoing collaborative research initiative on the theme of Therapeutic Environments.

- 5. In existing buildings, it is more difficult to apply dementia-design principles because of the existing structure. Some social housing providers try to include dementia design principles when re-fitting, re-modelling and re-furbishing sheltered housing schemes.
  - a) Guinness Trust used a range of existing resources to develop a design guide which is used to assess how dementia-friendly existing stock could be. It is then used when carrying out planned work and repairs.
- 6. A range of aids, adaptations and technology devices have been developed specifically with people living with cognitive impairments in mind. For example:
  - a) BRE is planning to develop a demonstration home on their site in Watford
  - b) AKW bathroom range
- 7. Stirling Dementia Centre is developing an <a href="maps">app</a> to assess how suitable a home is for someone with dementia. The dementia database called Iridis will then recommend changes that could be made.

#### LIVERPOOL HOUSE OF MEMORIES APP

My House of Memories allows people to explore objects from the past and share memories together. It was created by National Museums Liverpool and can be used by anyone, but has been designed for, and with, people living with dementia and their carers.

It enables people to browse through objects from across the decades, brought to life with multimedia, to reminisce about a range of everyday objects, from school life to sport. Objects can be saved to an individual's own memory tree, memory box or memory timeline. Personal profiles of different people can be created, so that they can save their favourite objects and look at them again. It contributes to people with dementia living well and provides an opportunity for carers to support people through memory activities that can be done together.

#### **ISSUES AND CHALLENGES**

#### 1. General

- a) While Dementia-Friendly design **principles** seem to be clear and commonly accepted amongst the cognoscenti, there appears to be little agreement on **how** those principles should be implemented in practice and seems to be little evidence to support what is best e.g. debates about patterned wallpaper and red loo seats; more evidence is needed.
- b) There are also debates about where good design, age-friendly design and dementia-design overlap and where they are distinctive. There are clear overlaps (e.g. good lighting, clear wayfinding etc) as well as possible differences or additional principles for people with dementia (e.g. scale) but careful thought and design could overcome many of these. Signage is often seen to be institutional.
- c) There is a belief that it will cost a lot, even for things that do not carry a high cost, but can make a significant difference. For example use of colour, contrast, and clarity of function in a room.
- d) Co-morbidities such as mobility problems and sensory impairment are not always recognised with the risk of a property being suitable for one impairment, but not for a co-existing one.

#### 2. In new build properties

- a) There is no incentive for mainstream builders and developers who anticipate turnover and do not target older people.
- b) Should new developments be age and disability-friendly or specifically dementia-friendly?
- c) Dementia-friendly design needs to be balanced with attractiveness to applicants. Depending on the particular design features, many people may prefer for their properties not to include them if they do not need them.
- d) Sometimes style wins over substance.
- e) Design standards in regulations are pared to a minimum. Part M 4 (2) and M4 (3) of the new Building Regulations are 'optional' and only apply to relevant developments such as disabled / wheelchair or specialist (including older persons) housing.
- f) Private retirement housing tends not to be dementia-friendly either in design or services. The term "dementia-friendly" is seen as negative for marketing purposes. Increased turnover and re-selling of properties, if they are not suitable for someone with dementia to remain in, can be profitable for providers.

- g) Available information on design has only limited reach. Not all commissioners, developers, architects, planners and providers have sufficient knowledge. This has training implications, e.g. for students of architecture.
- h) Limited budgets can lead to dementia-friendly design features being "value engineered" out, e.g. reducing size of windows and therefore natural light.
- i) There is an issue of financial viability, for example in relation to scale, although it is possible to build large numbers of properties while addressing issues of scale through design, e.g. clustering properties into smaller units.
- j) Ingenuity has to be used to ensure access to external space for wellbeing in the context of land value and size.

#### 3. Existing buildings

- a) Structure, fabric, access, wayfinding, and security concerns impose constraints in existing buildings.
- b) Costs for major modifications or adaptations can be high and lack of funding is an issue.
- c) There remains a lack of awareness and knowledge both of the potential difference that adapting the environment to keep people in their homes can make, and the design principles e.g. defensive planting. This applies to front line staff including social workers and those administering the Disabled Facilities Grant as well as development, repairs staff and the workforce generally.
- d) As with new build properties, there is no incentive, especially in general needs and ordinary housing, to make the properties more dementia-friendly.
- e) There is little evidence on the effectiveness of making adaptations, and embedding dementiafriendly design principles, for people with dementia living in existing buildings.
- f) There is also a belief that work will be a major disruption even when it is not.

#### 4. Aids and Technology

- a) While aids and devices are being developed <u>for</u> people with dementia, too many are not developed <u>with</u> people who have dementia. At best they tend to be consulted late in the development process.
- b) There is a tendency for the design of aids and adaptations to focus on physical rather than cognitive impairments.
- c) Poor understanding of the impact of dementia, e.g. visual distortions or use of technology when the user may be unable to learn how it works, means the devices may not be suitable.

#### ADDRESSING THESE CHALLENGES - WHAT NEEDS TO BE DONE?

#### 1. Practice

- a) Commissioners should ensure that dementia-friendly design features are included in building contract tender documents and are not "value engineered" out during build process.
- b) Operational staff and those with lived experience should be involved from the outset alongside designers/architects and developers.
- c) Housing providers with a percentage of occupants with dementia should consider employing a dementia specialist. (See case studies: Guinness p.43; Abbeyfield p.41; and Mr E p.23).

d) Innovative external spaces should be ensured even where there are site constraints – e.g. RMBI's accessible roof garden at James Terry Court.



Roof garden at James Terry Court, Croydon

- e) Inclusive design: Use 10 key <u>HAPPI</u> principles while using judgement in relation to suitability for people with dementia.
- f) Present and future occupiers should be consulted where possible

## 2. Raising awareness and training

- a) Good practice should be shared e.g. Housing LIN showcasing; ex-manager advising general needs providers on Dementia-Friendly design for cyclical repair and refurbishment; relevant membership bodies could do more in disseminating guidance and good practice examples.
- b) Design and dementia should be included in training for the housing workforce.
- c) Dementia design principles should be included in a range of professional curricula e.g. architects, surveyors, planners and other technical roles. Should RIBA and BRE be targeted?
- d) Disseminating the idea that good dementia design doesn't have to have a cost premium would be useful along with information of which dementia-friendly design features or products do not raise the cost.

## DESIGN PRINCIPLES THAT DO NOT HAVE TO COST A LOT - DAMIAN UTTON, POZZONI ARCHITECTS

- Colour contrast: i.e. floor/wall junction, kitchen worktop/wall junction, step in a floor, light switch/wall surface, wc seat/sanitaryware and surrounding floor/wall colours. But floors must have very little contrast between flat surfaces to avoid the (mis)perception of a step.
- Objects for orientation: can be less institutional than signage e.g. a large clock or artwork
  at the end of a corridor can be a memory trigger that their front door is along that corridor.
  Memory box or other object by someone'S front door can help them recognise that is
  their door although all people are different, sometimes a traditional door number or
  nameplate is sufficient.
- Making it obvious where the wc is painting all wc doors the same (contrasting) colour
  within a building gives a consistency of understanding. A clear and obvious pictogramme
  with a picture of a wc can also be helpful.

- Hiding inaccessible doors by painting out the same as the surrounding wall to avoid the frustration of trying to open a locked door as people with dementia may not understand why it is locked.
- No confusing patterns or lifelike representations on wallpaper, carpets, upholstery flower wallpaper may be perceived as real flowers.
- Clear where things are and where to go can certain doors be removed (subject to fire regulations and privacy issues)? Could kitchen cupboard doors be replaced with glass front, or no cupboard door so that the person can see where things are and act as a memory trigger for the need to have a drink of water, for example.
- e) Is a specific guide needed for ordinary housing that distils all the guidance out there?
- f) Should Homes and Communities Agency (HCA) non-mainstream housing design guidance be updated with current practice and guides?
- g) Conferences are a good forum e.g. Liverpool DAA on design for dementia in 2017

## 3. Improving guidance and lobbying

- a) Research is needed into the effectiveness of different design features to build up evidence. This would help to make the case.
- b) Dementia-friendly design principles should be overlaid with those for sensory impairments, physical disabilities, lifetime home standards etc to identify common ground. Co-ordination of design would be cost-effective and enable joint areas for lobbying of commissioners, policy makers, architects and developers.

#### c) Regulation

- i. Should lobbying take place for key design standards to be applied to more than just specialist housing?
- ii. Recent Housing Standards and Part M of the Building Regulation focus on visual and physical impairments. Standards that address cognitive impairments should be included in the Building Regulation.

## FINDINGS - SECTION 1: HOUSING ISSUES

## 1. SUGGESTED PRIORITIES FOR HOUSING RELATED FOLLOW-UP

## E. DATA COLLECTION AND RESEARCH

- 1. 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, for example the number of people with diagnosed or suspected dementia in providers' properties, and what service adaptations providers are making to their offer to be dementia-friendly, as well as undertaking research to generate evidence.
- 2. Research that is specific to housing and dementia is limited.
- 3. Obtaining funding for research in this area is really difficult as the <u>Housing and Dementia Research</u> <u>Consortium</u> can testify.
- 4. Survey responses and workshop discussions identified the following areas which could benefit from more research:
  - a) Innovation and practice across the country in all the domains to gain a more complete picture;
  - b) The actual and potential contribution of housing associations and HIAs in developing dementiafriendly communities;
  - c) The impact of poor or unsuitable housing on the health and wellbeing of people with dementia and their carers;
  - d) Comparison of outcomes for people with dementia where services are co-located or integrated and where they are not;
  - e) The triggers for people with dementia moving on from ECH and other home settings;
  - f) The number of people with dementia in current housing stock of different types;
  - g) The advantages and disadvantages of different housing models for accommodating people with dementia;
  - h) The effectiveness of making dementia-friendly adaptations and home improvements in supporting people with dementia to live well and safely in their own homes;
  - i) A longitudinal study into the effectiveness of different aids and technology devices in supporting people with dementia to remain living safely and well in their own homes;
  - j) Effectiveness of different ways of implementing a given design principle;

- k) Further work is needed to ascertain
  - i. the interconnections and degree of co-ordination between organisations providing information, advice and advocacy
  - ii. what the different sources of information and advice both general and dementia-specific, and national/local cover

and what scope there is for further improvement in both aspects;

I) The extent to which dementia-friendly design is being applied to neighbourhoods, and what is proving to be effective.

#### HOUSING AND DEMENTIA RESEARCH CONSORTIUM

The <u>Housing and Dementia Research Consortium</u> (HDRC) is a membership group that is committed to timely, high quality research focused on 'what works' in order to directly influence policy and practice in relation to housing with care and other forms of accommodation and care for people with dementia in the UK.

Now under the auspices of Worcester University's Association of Dementia Studies (ADS), the steering group comprises a number of housing providers who fund the co-ordinator, as well as the Housing LIN, ADS and the Alzheimer's Society.

It is currently contributing to research into Green dementia care in extra care and residential care settings.

The HDRC has a list of priority areas for research (see Appendices p.62).

- 5. More information is needed on the following:
  - a) Will <u>UTOPIA</u> study (using Telecare for Older People in Adult Social Care) include the needs of people with dementia and different housing settings?
  - b) Will <u>Centre for Ageing Better research</u> into the impact of adaptations specifically identify people with dementia?
  - c) The work being undertaken by BRE to develop a <u>dementia home demonstrator</u> and to hold workshops on supporting people with dementia.

# FINDINGS - SECTION 1: HOUSING ISSUES 2. OTHER HOUSING TOPICS

## **A. DEMENTIA-FRIENDLY HOUSING ORGANISATIONS**

- 1. There is probably reasonably good dementia-awareness amongst the managers of specialist housing providers in the social and voluntary sectors and amongst some general needs social housing providers who offer sheltered and extra care housing.
- 2. However, many people with dementia do not live in specialist housing and most do not live in social housing.
- 3. It is not clear how far the message has spread to non-specialist general needs providers or home improvement agencies.
- 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. Although it is difficult to get accurate information, the number of housing associations that are national members of the <a href="Dementia Action Alliance">Dementia Action Alliance</a> (DAA) seems low although others are involved in their local DAAs.
- 5. Signing up to commitments in the recently published <u>Dementia-friendly Housing Charter</u><sup>32</sup> should assist housing organisations to become dementia-friendly, provided they recognise the importance and value of doing so.

## ABBEYFIELD – BECOMING A DEMENTIA-FRIENDLY ORGANISATION

Abbeyfield has appointed a Head of Dementia Innovation and has developed a dementia strategy based on the acronym EMBRACE

## **E - EDUCATION AND AWARENESS**

- We will develop a skilled and effective workforce who are able to champion compassionate person centred/whole person care.
- We will help everyone to better understand the condition.

#### M - MIND, BODY AND SPIRIT

- We will work in a holistic way to enhance the mental, emotional, physical and spiritual well being of our residents with dementia.
- We will support carers, to ensure that they stay well whilst caring for people with dementia.

#### **B - BREATH OF FRESH AIR**

• We will seek to enrich the lives of people with dementia by connecting them with nature and the outdoors through Abbeyfield's 'breath of fresh air' programme.

#### **R - RELATIONSHIPS AND COMMUNICATION**

- We will put the needs of our residents and their families/carers at the heart of all relationships, seeking and acting on feedback.
- We will actively seek to work collaboratively with organisations that support our vision and can help us improve care and outcomes.
- Our internal and external communications will use language that is acceptable to people with dementia.

#### A - ARTS

• We will seek to enrich the lives of people with dementia through the arts by offering access to a wide range of creative opportunities.

## **C - COMMUNITIES**

- We will support the development of dementia friendly communities by making links, sharing knowledge, expertise and resources
- We will seek to improve and enhance the lives of our residents through connections with local communities, agencies and partners

## **E - ENVIRONMENT**

• We will assess, adapt and develop our environments and services to make sure they are inclusive for people with dementia

#### SUCCESSES INCLUDE:

- Dementia training programme
- Working with Uni of Worcestershire to develop a dementia care coaches programme
- HR department involved in supporting strategy
- Resident engagement group working through DEEP
- Roving art gallery of work by people with dementia
- 'Breath of Fresh Air' award-winning programme reconnecting people to nature

## GUINNESS PARTNERSHIP - BECOMING A DEMENTIA-FRIENDLY ORGANISATION

Guinness Partnership commissioned a piece of work from Institute of Public Care (IPC) about the steps needing to be taken to become a dementia-friendly organisation resulting in a <u>report</u>, *Becoming a Dementia-friendly Organisation*.<sup>33</sup> They then appointed a dementia advisor to coordinate the housing and dementia project with the aims of:

- 1. Ensuring their homes and services meet the needs of their customers with dementia.
- 2. Enabling their customers to live independently for as long as possible.
- 3. Assisting and promoting their well being.
- 4. Improving the organisation's ability to provide amazing customer services through organisational culture/staff behaviours and building on their capabilities

This involves work in a number of areas:

- Awareness raising for staff and customers many have attended Dementia Friends sessions
- Training face-to-face training for all front-line staff and a bespoke e-learning package
- Dementia-friendly design specifications including: a guide for staff use; working with
  other projects within Guinness to ensure any changes take into account dementia-friendly
  principles; improving the offer of aids and adaptations; involvement with the planned
  maintenance programme; and developing a dementia-friendly community resource,
  Jubilee House
- A dementia-friendly customer package Its aim is to make sure that the service is provided in the way that the individual customer requires with a view to making remaining at home and being independent a little easier. This might include some of the following:
  - A choice of small adaptations like coloured toilet seats, grab rails, light switch covers, different coloured front doors. They also considered offering glass fronted kitchen units were a resident to ask/need for this but the customers' response in focus groups was not that positive.
  - They also ensure that they can add a flag on customers' accounts detailing how they
    would like the service tailored to them. For example, they may request confirmation
    letters rather than the usual verbal confirmation of appointments; they may want
    family members texted or e-mailed to confirm appointments.
  - Treating some repairs with a higher priority if they are adversely affecting their symptoms (e.g. flickering lights).
  - There has also been some assistive technology that Guinness can signpost the customer to try or offer for them to trial for the organisation.
- A dementia knowledge bank including: clear accessible information; dementia champions role; information point for customers; better customer profile information
- Developing dementia champion roles

Some good progress has been made on all these fronts. They have over 1,000 employees who have done the Dementia Friends training, have developed internal guidance on dementia design and have refurbished a community space in Havant (Jubilee Centre) to dementia friendly design standards. They are undertaking assistive technology trials with customers and have developed an e-learning module on dementia for staff.

For more about Guinness Trusts' work on living with dementia, visit:

http://www.guinnesspartnership.com/case-study/dementia/ http://www.dementiaaction.org.uk/news/23483\_5\_minutes\_with\_wendy\_wells

## **B. HOUSING SUPPLY AND MODELS**

- 1. A shortage of suitable housing is recognised as a significant problem across the board, not only for people with dementia.
- 2. 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.
- 3. The supply of new housing is inextricably linked to questions of standards, design and type/models of new homes and the proportions needed of each. Questions remain about what is enough, which standards should apply to which housing typologies, and the proportion of different types of housing.
- 4. In addition, views differ as to whether housing should be group-specific or inclusive, whether with reference to people from minority ethnic groups, people with dementia, or sub-sets combining a number of special needs or characteristics. Research is needed.
- 5. Because every person's needs and preferences are different, a variety of housing is needed: from ordinary adaptable housing built to for example Lifetime Home Standards at a minimum; through design principles such as <a href="https://example.com/harper-such as-harper-such as-harper-s
- 6. Not only do people make different choices, but local circumstances also differ, for example, in their concentration of particular ethnic groups. The Housing LIN's online Strategic Housing for Older People (SHOP) tools are a good starting point but more work is needed that incorporates age- and disability-friendly ordinary housing of different tenures, and also sub-sets of particular population groups.
- 7. Government policy which has tended to prioritise 'first time buyers' over 'last time movers' or 'later life buyers', a lack of recognition that addressing the housing needs of older people will help all other groups, and a lack of will amongst developers, all contribute to an inadequate supply of suitable new housing for older people.
- 8. There is inadequate incentivisation to build all properties to Lifetime Home Standards or the equivalent. Given that most older people and those with dementia live in ordinary rather than specialist housing, this is a critical issue.
- 9. Affordability is also an issue. This applies both to the cost of moving and the rent or purchase price of the new property.

- 10. Research is needed into the housing options being developed that are targeted at, or inclusive of, people living with dementia; what would best meet the needs and aspirations of people with dementia from particular minority groups; and the advantages and disadvantages of different models and approaches. These issues are a key research priority for the <a href="Housing and Dementia Research Consortium">Housing and Dementia Research Consortium</a>, but so far, funding has not been identified.
- 11. There are examples of various models of dementia friendly specialist housing:
  - a) Extra Care housing using an integrated model e.g. <u>Hare Hill</u><sup>35</sup> in Rochdale
  - b) Specialist or dedicated dementia schemes e.g. Flowers House<sup>36</sup> in Bletchley
  - c) Extra Care schemes with separate wings e.g. <u>Llys Jasmine</u><sup>37</sup> in Mold, Wales
  - d) Hybrid models which combine housing and other types of provision such as residential or nursing care for people with dementia e.g. <u>Belong villages</u> in the North West and Joseph Rowntree Foundation's Hartrigg Oaks in York
  - e) Abbeyfield households
- 12. There are also a variety of models in other countries, but the different conceptual and legislative framework in relation to care registration needs to be borne in mind as they may not be directly transferrable, for example:
  - f) Hogewey village in Holland
  - g) Bellmere village<sup>38</sup> in Australia

## C. AIDS, ADAPTATIONS, REPAIRS AND HOME IMPROVEMENTS

- 1. An inability to cope with day-to-day home and garden maintenance, and/or unsuitability of the home is likely to be a trigger for moving if help not available. This is corroborated by the Elderly Accommodation Counsel's (EAC) HOOP appraisal tool findings cited in *The Value of Sheltered Housing*. <sup>39</sup> This does not seem to be a good reason to have to move from your own home, as help with many of these issues is available if the person is aware of it and is supported to access (and manage) it.
- 2. Aids, adaptations, repairs and home improvements can make an important contribution to enabling people with dementia to live well and safely at home and HIAs do a good job, but more is needed.
- 3. Simple and inexpensive aids and adaptations can make a big difference, for example white boards as prompts.
- 4. That said, there is a dearth of evidence on the use and effectiveness of aids and adaptations for people with dementia.
- 5. Accessing aids
  - a) There are HIAs and others such as local Age UKs who provide information and advice as well as help to access aids and adaptations.
  - b) There is a wide range of products available but it is difficult for a member of the public to know where to look and what is suitable for them.
  - c) There is a failure of effective marketing to self-funders. People in need of adaptations have limited access to this information in a responsible way, seemingly dependent on advertising in the weekend newspapers and supplements. Whilst in the main there is no issue with the quality of these products, the cost reflects the inevitable marketing mark-up.
  - d) A number of independent living centres, for example the one in <u>Knowsley</u> can assist, as can websites but people need to know they exist.

- e) However, people ideally need individual assessment and advice as to what is suitable for them, and support in order to access it, regardless of income or whether they or someone else pays for it. This seems not to be readily available for the vast majority living in ordinary housing.
- f) Those with eligible care needs may get advice from an occupational therapist, though not necessarily as quickly as needed.
- g) There is also ignorance amongst some professionals on what is available
- 6. Funding of aids, adaptations and home improvements
  - a) HIAs can help people to access Disabled Facilities Grant (DFG) but the grant is limited and tends to be used for physical disabilities and sensory impairments rather than helping people to overcome the challenges of cognitive impairments.
  - b) There are no drivers for the DFG to focus on adaptations that address cognitive impairments.
  - c) Worcestershire County Council is trialling a "dwelling grant" from DFG specifically for people with dementia (See case study p.18).
  - d) Occupational therapists may take the view that it is not worth installing an expensive adaptation as the person's dementia means they may not be able to benefit from it for any length of time, and the disruption of the work can also causes distress.
  - e) Some social housing providers will pay for adaptations, some will not; the picture is very mixed.

## **HYNDBURN HOMEWISE, LANCASHIRE**

A home improvement agency in Accrington, Lancashire runs Memory Matters which support people living with memory issues and their carers.

The project, funded by NHS East Lancashire CCG, supports people to stay at home continuing to live independently and keeping them safe and out of hospital and residential care.

Simple innovations in the home can make all the difference to the visual and orientation problems people with dementia can face. Examples include changing white grab rails in bathrooms to blue or light switches to red or blue to improve visibility, the use of memory aids to remind people to lock doors or close the fridge, the use of signage and pictures to aid orientation.

For further information see article in February/March 2016 edition of Alzheimer's Society's Living with Dementia magazine: <a href="https://www.alzheimers.org.uk/site/scripts/documents\_info.php?documentID=3198&pageNumber=6">https://www.alzheimers.org.uk/site/scripts/documents\_info.php?documentID=3198&pageNumber=6</a>

7. Aids and adaptations are likely to become more technology based. This can be an issue for people who already have a cognitive impairment if use of a device needs to be learnt.

## D. TECHNOLOGY

- 1. Use of technology to support people with dementia appears to vary. There are pockets of innovation but not widespread application. There appear to be pilot studies but little follow through.
- 2. There is widespread use of <u>Just Checking</u>, locator devices and remote door opening amongst local authority service users in some areas and also in some housing with care schemes, but experience of front-line staff suggests that there is ignorance amongst primary care professionals as to what is available.
- 3. Specific knowledge and expertise in relation to dementia-friendly technology is not widely available.
- 4. New products are emerging all the time, e.g. use of TVs to prompt people at home but the disembodied voice may not suit everyone.
- 5. There are numerous products available but they can be confusing. The best ones have been codesigned with people with dementia and their carers from the outset so they are user-friendly.
- 6. Technology may reassure family members so it needs to be clear for whose benefit it is provided.
- 7. The <u>Alzheimer's Society Dementia-friendly technology charter</u><sup>40</sup> aims to help people with dementia to benefit from technology and outlines good practice principles.

## **HULL CITY TELECARE TEAM**

<u>Hull City Council's Telecare Team</u> was established to improve the safety and health of Hull's residents, particularly those who are older, have dementia, are carers or who have been recently discharged from hospital. Initially providing basic packages including Lifeline home unit and pendant with environmental sensors such as smoke and carbon monoxide detectors, the team now also offers a wider range of telecare to support people with more complex needs. Hull's telecare provision is an integrated service, with the eight Telecare Team staff funded by the City Council's Social Care department, telecare sensors funded by NHS Hull Clinical Commissioning Group, and the Council's Housing control centre Kingston Care providing monitoring and installation.

Telecare is supporting Hull to become a Dementia Friendly City. There are approximately 800 people in Hull registered with care services who are living with dementia. Using telecare solutions means that people with dementia are safeguarded, and their carers are under less stress.

The Telecare Team is an integral part of Hull City Council's re-ablement services, and as such, works closely with local hospital discharge teams. A member of the telecare team is based in the hospital two days per week working on the Acute Assessment Unit and short stay wards, working in partnership with clinical staff and social workers to ensure patients are discharged as quickly as possible with the appropriate support in place.

The Telecare Team also supports the Council's intermediate care units, such as Thornton Court which houses 14 semi-independent flats.

#### **ROSE'S STORY**

Rose, a woman with dementia living in an extra care scheme was at risk at night, becoming disorientated and disturbing the neighbours. She was enabled to remain living there through technology and Hull Out of Hours Team (HOOHT) backup. Rose agreed to have a bed occupancy sensor and property exit door sensor fitted to connect to her Lifeline. If Rose left her bed during the night and failed to return within 15 minutes HOOHT would be alerted. The door sensor was active from 10pm to 7am and would raise an alert if Rose opened the door and did not return within 5 minutes.

## For more information, visit:

http://www.hullcc.gov.uk/portal/page-\_pageid=221,686965&\_dad=portal&\_schema=PORTAL

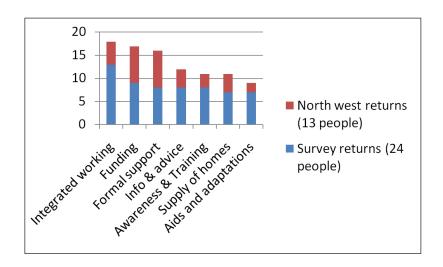
# FINDINGS - SECTION 2 THE BIGGER PICTURE

In addition to the housing-specific topic areas covered in Findings 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, and the findings are touched on very briefly here. The DHWG holds the full information from the consultation on these topics.

In the survey, focusing on the bigger picture, 37 people responded to the following question: Which of the three **wider-ranging factors** above would you say are in most urgent need of change/improvement to enable people with dementia to remain living well in their own homes?

## The top five were:

Integrated working	18	49%
Funding	17	46%
Formal support	16	43%
Information and advice	12	32%
Awareness and training	11	30%



Some of the areas prioritised for attention from a housing sector perspective in Findings Section 1 have wider importance and more general relevance but are not covered again in this section. These include:

- 1. Access to wide-ranging information, advice and advocacy
- 2. Integrated working, shaped around the person with dementia and their informal carers across sectors, disciplines, services and policies
- 3. 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

- a) Budget cuts and inadequate funding have a significant impact. They result in a range of shortages and quality issues across most domains.
  - i. Local authority budget cuts are having a significant impact on the availability of good quality formal (e.g. adult social care, mental health services and home care services) and informal services (e.g. befriending and peer support) for people with dementia, which in turn is impacting on the National Health Service, in particular hospitals.
  - ii. Provision of awareness raising and training (across a range of issues in addition to dementia within entire workforce) is impacted by inadequate funding.
  - iii. The Better Care Fund(iii) is available for aids and adaptations but is probably not sufficient to meet the needs.
  - iv. Welfare benefit cuts affect the revenue income of housing providers and their ability to fund housing-related support and other valuable but less essential services such as activities facilitation.
  - v. Reduced grant levels and less direct state capital investment in Affordable<sup>(iv)</sup> and social housing has resulted in a slowing down in the supply of suitable homes.
  - vi. Achieving funding for research into housing and dementia issues is hugely challenging.

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

- a) There are some excellent initiatives to promote inclusion such as <u>DAA</u>s (Dementia Action Alliances), <u>DEEP</u> (Dementia Engagement and Empowerment Project), <u>TIDE</u> (Together in Dementia Everyday) and areas working towards becoming <u>dementia-friendly communities</u>, but there is a long way to go before people with dementia are treated as equal citizens.
- b) Dementia awareness campaigns such as <u>Dementia Friends</u>, that launched by Public Health England and various other initiatives have raised awareness of dementia.

<sup>(</sup>iii) The Better Care Fund (BCF) is a programme spanning both the NHS and local government which seeks to join-up health and care services, so that people can manage their own health and wellbeing, and live independently in their communities for as long as possible. It incorporates the Disabled Facilities Grant, a grant for adaptations to the home, administered by lower tier local authorities.

<sup>(</sup>iv) A capital "A" is used to denote the government's "Affordable housing" programme where landlords can charge up to 80% of the market rent, as distinct from the generic use of the term.

- c) Housing providers can make a positive contribution to the development of dementia-friendly communities and some are active in their local Dementia Action Alliances. For example, Waltham Forest Housing Association was instrumental in the formation of their local DAA.
- d) Societal attitudes including ageism remain a significant issue, with apocalyptic narratives around dementia, and stigmatising of those living with it. This is often compounded by additional misconceptions about dementia or differing cultural attitudes towards it in certain communities, such as in the <a href="South Asian community">South Asian community</a>. In the <a href="LGBT community">LGBT community</a>. 41, 42 In the <a href="LGBT community">LGBT community</a>. 43, 44 stigma towards those with dementia may be overlaid with fear of prejudice towards their sexuality. Training programmes need to cover these aspects.
- e) The media have a fundamental role in perpetuating current negative attitudes, or positively reshaping them. The negative language used is currently being countered by the Dementia Words Matter campaign. There is still a long way to go.

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

- a) This emerged clearly as a major issue. Although the Dementia Friends and other campaigns have improved both public and professional awareness of dementia, there was a consensus that Dementia Friends sessions do not constitute training. Organisations whose staff come into direct and regular contact with customers who have dementia need more robust training. Workforces across all sectors appear to lack the knowledge and skills to:
  - i. Understand dementia and the individualised experience and manifestation of it, as a result of a range of personal features and circumstances;
  - ii. Effectively communicate and support people with dementia and their carers;
  - iii. Effectively implement relevant aspects of the law; for example, the Mental Capacity Act.
- b) Staff training was one of the two most important things that the Service User Reference Panels (SURPs) thought needed improving, and the recent <u>Alzheimer's Society report Fixing Homecare</u><sup>45</sup> identified that only 2% of respondents thought their paid carers had had sufficient training in dementia.
- Awareness raising and/or training is needed in the social care and health sectors about housingrelated issues and options including:
  - i. The importance of including housing professionals in the care and discharge planning of their residents:
  - ii. The housing models and services available in the locality and what they can and can't provide, as well as sources of aids, adaptations and assistive technology.

The next three areas illustrate the valuable contribution the housing sector can make, despite the domains being much broader than housing:

## 4. RELATIONSHIPS AND INFORMAL SUPPORT NETWORKS

- a) Peer support and other informal networks amongst people with dementia and their carers are highly valued, promoting well-being and fulfilling a preventative function.
- b) The housing sector facilitates these by providing venues and working in partnership with others.

- c) Abbeyfield is cited as a good example of an organisation using volunteers to support older people, including those with dementia, in the University of Stirling <u>ASUME study</u> which looks into the role of volunteers in dementia care.
- d) Nevertheless, voluntary services such as befriending may be seen as soft targets for cuts in a climate of scarce resources.

## THE MENTAL HEALTH FOUNDATION AND HOUSING & CARE 21 – PEER TO PEER SUPPORT GROUP

The original pilot project groups ran for 18 months to November 2013, funded by City Bridge Trust, Salters Company and Rayne Foundation. This tested the effectiveness of facilitated peer to peer support groups for the well-being of older people with dementia in retirement and Extra-Care Housing within Housing & Care 21's courts. Two of the three original groups are still running. They have been sustained by either volunteers or by Housing & Care 21 providing a budget to enable care staff to be paid for the extra hours.

The learning and good practice from the original project was identified through an <u>evaluation</u><sup>46</sup> by the Joseph Rowntree Foundation (JRF) and used to scale up the project and to include residents who are a trisk of loneliness, but without dementia. A <u>guide to running self-help groups</u> in sheltered and extra care accommodation for people with dementia<sup>47</sup> was produced.

The Mental Health Foundation (MHF) subsequently received Big Lottery funding to extend the project to work with 375 residents over 3 years. Also, Notting Hill housing has joined the project to offer more schemes for the project to take place in. The issue of sustainability is being built in right at the outset of the next cohort of groups, allowing more time for volunteers to be identified.

Residents name their groups and influence the content although there is a programme which can be referred to if residents are not forthcoming with ideas. Activities include making memory boxes, putting on a play, making a wall college and writing a handbook to welcome new residents. The groups are facilitated by the MHF for the first six months with a focus on the group being self-sustaining after that time.

On-going evaluation of the impact of the project is being undertaken by the Mental Health Foundation.

For further information visit:

https://www.housinglin.org.uk/Topics/type/The-Dementia-Self-Help-Project/

# 5. ACCESS TO PRACTICAL HELP AND SUPPORT SERVICES FOR PEOPLE WITH DEMENTIA AND INFORMAL CARERS WHETHER FROM THE VOLUNTARY, SOCIAL CARE, HEALTH OR HOUSING SECTORS

a) There are some good support services including those provided by the housing sector but they are insufficient to meet demand and as identified above, are adversely affected by funding issues, silo-working and training issues.

- b) Housing providers and <u>home improvement agencies</u> provide a range of practical services such as repairs and handyperson services as well as housing-related support and other innovative services.
- c) A number of HIAs work with local health services to provide <a href="https://hocs.ncbi.nlm.nih.google-burg-new-no-services">hocs.ncbi.nlm.nih.google-burg-no-services</a> which are inclusive of people with dementia. <a href="https://www.care.nd.ncbi.nlm.nih.google-burg-no-services">Care and Repair England</a> have just published <a href="https://www.naneservices.nd.ncbi.nlm.nih.google-burg-no-services">hocs.ncbi.nlm.nih.google-burg-no-services</a> which are inclusive of people with dementia. <a href="https://www.naneservices.nd.ncbi.nlm.nih.google-burg-no-services">hots.ncbi.nlm.nih.google-burg-no-services</a> which are inclusive of people with dementia. <a href="https://www.naneservices.nd.ncbi.nlm.nih.google-burg-no-services">hots.ncbi.nlm.nih.google-burg-no-services</a> which are inclusive of people with dementia. <a href="https://www.naneservices.nd.ncbi.nlm.nih.google-burg-no-services">hots.ncbi.nlm.nih.google-burg-no-services</a> which are inclusive of people with dementia. <a href="https://www.naneservices.nd.ncbi.nlm.nih.google-burg-no-services.nd.ncbi.nlm.nih.google-burg-no-services.nd.ncbi.nlm.nih.google-burg-no-services.nd.ncbi.nlm.nih.google-burg-no-services.nd.nih.google-burg
- d) The home care service is vital for people with dementia who need support at home. It is particularly badly affected by recruitment and retention challenges making a reliable, skilled workforce even more difficult to achieve.

## ORBIT CARE AND REPAIR HOME FROM HOSPITAL SERVICE

Orbit housing association provides a home from hospital service in Suffolk. The service provides advice and practical support to older people who can't return home following hospital treatment due to changes in their circumstances. This might be due to reduced mobility, problems with bathing or difficulties getting in and out of their home. The hospital discharge team can arrange for Orbit to carry out a home assessment. They will offer advice and practical assistance to remedy any issues identified, allowing the person to return home in safety and comfort.

## In addition they offer:

- home repairs and adaptations;
- handy person service;
- home safety advice and information;
- advice and information on paying for building work;
- housing options;
- advice, information and training on hoarding issues-Hoarding Support Service;
- assistive technology.

For more information on Orbit's Care and Repair services, visit:

https://www.orbit.org.uk/living-in-orbit/independent-living/care-and-repair/

## COMMUNITY LOCKSMITHS, EXTRACARE CHARITABLE TRUST

<u>The Enriched Opportunities Programme</u><sup>48</sup>, <sup>49</sup> was introduced in the ExtraCare Charitable Trust's housing with care schemes following research by Professor Brooker. It identified five key elements needed to work together to bring about radical improvement in the quality of life of people with dementia:

- Specialist expertise
- Individualised assessment
- Activity and occupation
- Staff training
- Management and leadership

Specialist expertise is provided in the form of Locksmiths who work with residents who are identified as vulnerable, particularly those living with dementia, to "unlock" their potential. Locksmiths

- Investigate concerns such as walking with purpose, distress responses, hydration, nutrition...
- Liaise with family members where appropriate
- Liaise with other health and social care professionals
- · Participate in care plan reviews, safeguarding, or best
- interest meetings
- Make referrals to other services e.g. Admiral Nurses
- Complete an 'Enriched Profile'

The Trust received funding for a pilot study from October 2014 – 2015 to extend the Locksmith service to vulnerable individuals living in the wider community.

As part of the Discharge to Assess service, the Locksmith worked with the care team and occupational therapist to support individuals identified in hospital as needing extra support when returning home. The team supports the person for around six weeks.

They also worked with the integrated neighbourhood team to support vulnerable individuals identified by GPs to avoid crises, relocation or hospital admission.

During the pilot year, around 60 individuals and their families were supported in Coventry, of which 69% remained living at home and avoided moving to care settings.

The Locksmith intervention costs around £828 per client including salary, training, activities budget and supervision. This compares to an average weekly cost of £599 for residential care and £799 for nursing care. During the pilot the local authority reduced the number of beds in use in one care home from 12 to 6 and the Locksmith's hours were increased from part-time to full-time mid-pilot.

More about the innovative locksmith programme can be found at: <a href="http://www.extracare.org.uk/newsroom/local-news/extracare-wins-outstanding-approach-to-innovation-at-ukha/">http://www.extracare.org.uk/newsroom/local-news/extracare-wins-outstanding-approach-to-innovation-at-ukha/</a>

## 6. MEANINGFUL ACTIVITY

- a) This is of fundamental importance to people living with dementia in order to have a sense of personhood, self-esteem and enjoyment. It needs to be personalised.
- b) The housing sector can and does contribute to this in a number of ways including:
  - i. Facilitating activities in its own schemes life story work, reminiscence groups, dementia cafés;
  - ii. Supporting involvement in activities and identifying individual's interests e.g. ExtraCare Charitable Trust's Locksmith programme;
  - iii. Providing venues for others to provide activities e.g. Alzheimer's Society's use of Cambridgeshire's sheltered schemes<sup>50</sup> and The Guinness Partnership Jubilee Centre;
  - iv. Getting to know individuals using approaches such as 'this is me' charts, and seeking ways to engage them meaningfully in day to day activities, e.g. giving responsibility for watering plants;
  - v. Innovative initiatives e.g. Abbeyfield's Golden Gallery art exhibition and an Australian HammondCare example of personalised music playlists on individual iPods outlined on page 17 of <u>Grand Dementia Designs</u>.<sup>51</sup>
- c) Challenges can include:
  - i. inadequate understanding of dementia and communication skills;
  - ii. increased workloads;
  - iii. funding cuts resulting in more limited job descriptions and less flexibility and responsiveness.

And finally, a very wide-ranging topic that could be the subject of a whole report in its own right:

# 7. LOCAL AND NATIONAL POLICY AND REGULATORY FRAMEWORK THAT SHAPES, SUPPORTS OR ENABLES THE FACILITATORS IN THE ABOVE DOMAINS

- a) A whole raft of legislation and regulation frames and affects the funding and provision of housing and associated services: housing legislation, planning, building and welfare regulations; various health laws; and the Integration and Better Care Fund Policy Framework to name but a few. A small selection of laws of specific relevance to people with dementia and other cognitive impairments is picked out here.
- b) The Care Act 2014, Mental Capacity Act 2005 and Equality Act 2010 are all progressive laws which together should promote equality, citizenship, empowerment and wellbeing for those with disabilities and cognitive impairments.
- c) Implementation appears to be marred by ignorance or incompetence, workload issues, expedience and/or lack of confidence. This applies to staff across the housing workforce and health and social care sectors as, for example, the <a href="House of Lords Inquiry into implementation">House of Lords Inquiry into implementation of the Mental Capacity Act<sup>52</sup> concluded.</a>
- d) There are a number of issues of particular relevance to the housing sector:
  - i. The signing and relinquishing of occupancy agreements when the person with dementia lacks/has lost the mental capacity to agree and there is no Lasting Power of Attorney or deputyship in place.
  - ii. At present, the mechanism for authorising a deprivation of liberty in a housing setting for the purposes of care and treatment is via the Court of Protection. Since the Cheshire West judgement, the deluge of applications from care homes appears to result in some local authorities dismissing housing providers' concerns in this area.
  - iii. The acid test for deprivation of liberty still requires further testing and clarification in the courts.

- iv. The Law Commission in March issued its <u>report and draft legislation</u><sup>53</sup> amending the Mental Capacity Act 2005 and deprivation of liberty arrangements, but the government has yet to decide whether and when some, or all, of the recommendations will be introduced.
- e) There is no specific regulation of the physical environment of people with dementia living in their own homes in specialist housing, as the care delivered is classified in the Health and Social Care Act 2008 as personal care. This can result in someone with reduced mental capacity to control their own home environment not necessarily receiving the support and protection they may need.
- f) Most NHS care is free at the point of delivery, while local authorities have the power to charge for social care, subject to a financial assessment. Most support provided to people with dementia is classified as social care. This can cause significant worry amongst families who have a loved one affected by dementia as there is no upper limit to the amount the person may have to contribute.

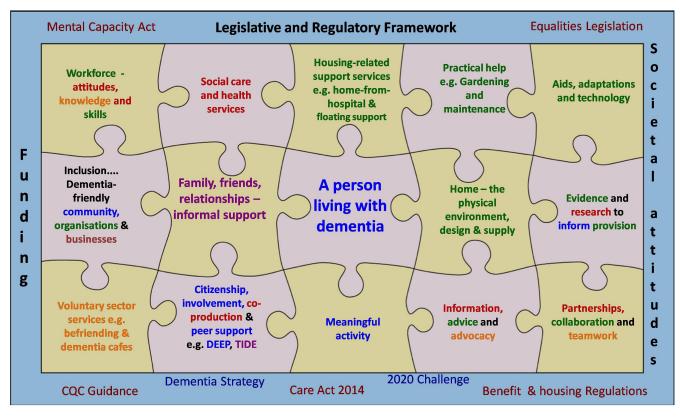
## **INTER-DEPENDENCE OF DOMAINS**

A point which was very clear from discussions was the interconnectedness of all the domains. Although identified separately, they 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.

The aspirational jigsaw below illustrates this point and suggests where, as a society, we need to get to.

## PERSON-CENTRED COMMUNITY SUPPORT



## THE DESTINATION – AN INCLUSIVE COMMUNITY

# **CONCLUSIONS**

- 1. Across all domains there are examples of good practice and pockets of innovation but the picture is fragmented and there is not consistent implementation across the country.
- 2. 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, and all the different pieces need to dovetail.
- 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 collection 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 by commissioners, planners, architects, policy makers and housing organisations of existing guidance, tools and evidence. 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.

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- 7. Funding pressures across the board, and their knock-on effect on the supply of practical help, formal care and support, voluntary sector services, aids, adaptations and home improvements, new homes, and workforce training, are identified as adversely affecting the ability of people with dementia to live well and safely in their own homes.
- 8. A lot of work remains to be done for people with dementia to feel that they are treated as equal citizens and for those with dementia from certain minority groups to feel comfortable seeking information, advice and support. The media have a central role to play in re-shaping narratives in relation to dementia.
- 9. Within each of the five housing priority areas, suggestions have been made as to how the current challenges could be addressed, 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.

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## **ARE WE NEARLY THERE YET?**

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

## **APPENDICES**

## **METHODOLOGY**

A project team comprising the Housing LIN, Homeless Link, Foundations and the Life Story Network was set up to steer the project with the support of an advisory group which would represent the DHWG and give advice at key points in the project.

A survey (see appendix) was devised using the domains listed above to obtain a broad picture of the position on the ground. It:

- sought to identify patterns of practice (both good and bad) as well as common issues and barriers within each domain
- invited ideas or examples to overcome the barriers
- asked if there was a particular role for the housing sector within each domain

The survey was targeted mainly, but not exclusively, at housing professionals and they were asked only to respond to questions on domains of which they had knowledge or experience. They were not expected to address every question. The purpose of the survey was to enable pooling of the knowledge and experience of respondents, and not to produce statistically robust data.

53 surveys were sent out, 22 to members of DHWG and 31 others (8 Housing LIN regional leads, 7 additional housing providers, 4 architects, 3 independent housing consultants and various other specialists). There were no public sector professionals asked to respond to the survey at this stage.

45% (24) of surveys were returned, 14 from members of DHWG, and 10 others.

In addition to the full survey being sent out, questions A & B were considered at a Housing LIN Northwest regional meeting and thirteen people provided a response just to these two questions.

The survey data was supplemented by a workshop session of 13 members of the DHWG in which eight topics were discussed in two facilitated groups:

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- Well-informed, aware and skilled workforce
- Supply of suitable homes for people with dementia and potential new models
- 3. Maintenance, repairs, aids and adaptations
- 4. Assistive technology

- Inclusion, absence of stigma, DF communities (with particular emphasis on people with protected characteristics)
- 2. Access to wide-ranging information, advice and advocacy
- 3. Integrated working
- 4. Access to support services including practical help

The emphasis was on garnering the particular knowledge and expertise of those present with contributions recorded in an information grid.

Data from both the survey and workshop were collated and the key points from each topic distilled into a Key Findings record. This was then further reduced into a five page summary for discussion by the Advisory Group who considered which topics should be prioritised for further work in a second phase of the project.

In addition, three questions were sent to the Alzheimer's Society for discussion by Service User Review Panels:

- 1. What helps you to live independently?
- 2. What makes living at home more difficult
- 3. What are the two most important things that you think should be improved? Can you tell us why?

Four panels were able to come back with their views within the timescale.

Appendices 63



## LIVING WELL AT HOME WITH DEMENTIA SURVEY

Enabling people with dementia and their carers to live independently and well in their own homes if that is their preference....we want to hear from you

- What is happening out there?
- What is working well?
- What is not working well?
- Who should do what to improve the situation?

## Why this project?

In the 2020 Dementia Challenge Implementation Plan, the Dementia and Housing Working Group (D&HWG) is included as one of the channels through which the Department of Health will work towards enabling 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)¹. The Housing LIN, Sitra/Homeless Link and Foundations are undertaking a project on behalf of the D&HWG to identify some of the factors at play and explore the role of housing and its associated services in achieving this aim. The project is expected to support the UK Dementia Envoy David Mayhew in undertaking his role.

## How wide is our focus?

A range of factors can help people with dementia (and their partners) to remain living well and independently in the home of their choice. Alternatively those same elements can be barriers. Some relate to the built environment, some to the wider social environment. In the first phase of the project we are looking at a broad range of relevant factors. The housing sector may have considerable control or influence over some of these and relatively little over others. In the second phase we will focus in greater depth on areas in which the housing sector has a significant role to play with the aim of identifying potential solutions.

## What do we mean by the housing sector?

By housing sector, we mean all organisations that design, build, develop or manage housing of all tenures, as well as those involved in arranging aids, adaptations and repairs to ordinary or specialist housing. By specialist housing we include age-exclusive developments such as sheltered housing and retirement communities, extra care housing as well as supported housing. Importantly, we include not only buildings but also the services these organisations provide and the workforce they employ or contract with.

<sup>&</sup>lt;sup>1</sup> DH Prime minister's Challenge on Dementia 2020 Implementation Plan 2016 5.76

## How are we doing it?

- A survey targeted at members of the Dementia and Housing Working Group and selected professionals to get a broad picture of what is happening on the ground
- Obtaining the views and experience of people with dementia and their carers through a number of existing channels
- Holding workshops for professionals in three regions of the country
- Some telephone interviews
- Asking providers for cases studies to illustrate the issues raised

## The survey

Please answer the questions on which you feel you have knowledge or experience and return it to <a href="mailto:sue@suegarwood.co.uk">sue@suegarwood.co.uk</a> by the end of Tuesday 13th December.

## **Case studies**

We want to get a picture of what is happening in reality, so we would welcome case studies to illustrate the points you make.

as you wish.
Name – optional but very helpful
Type of organisation and role within it
Contact details in case we want to follow up any points – optional but again, very helpful
e-mail: Phone number:
I am happy to be contacted for further information (Insert X in relevant box)
Yes No
Confidentiality and anonymity:
We would appreciate having your name so that we can follow up any points you make. Your identity will not be revealed in our reports. Where we include a quote to illustrate a point we will cite the originator in terms of role or type of organisation. We will contact you for consent if you could be identified by the process of deduction.
Please save your answers as a word document attaching your name or organisation's name to the filename before returning it to <a href="mailto:Sue@sueqarwood.co.uk">Sue@sueqarwood.co.uk</a> by the end of Tuesday 13 <sup>th</sup> December
Thank you.
Please go to the next page for the first question
We very much appreciate your time in completing this survey. Apart from questions A & B on the next page which we'd like everyone to respond to if

you can, you need only answer questions on the particular topics you know

about and have something to say.

By answering this survey you will help us build a picture. Please answer as many questions

The following wide-ranging factors can help people with dementia to remain living well and independently in their own homes. Alternatively they can be a barrier either because they are not available or they are not working as they should.

- 1. Design of homes
- 2. Maintenance, repairs, aids and adaptations in existing ordinary and specialist housing
- 3. Assistive technology
- 4. Neighbourhood design
- 5. Supply of suitable homes including specialist housing including potential new housing models in ordinary or specialist housing
- 6. Access to wide-ranging information, advice and advocacy
- 7. Access to practical help and informal support networks friends, family and neighbours for example
- 8. Inclusion and absence of stigma an informed public and dementia-friendly community
- 9. Access to support services for person with dementia and family carers voluntary sector, health, social care, housing-related and local groups for example
- 10. Integrated working, shaped around the person with dementia and their family carers across sectors, disciplines, services and policies
- 11. Dementia-friendly organisations, in particular housing organisations ethos, policies, procedures, practice and training
- 12. Well-informed, aware and skilled workforce across all sectors and industries including housing
- 13. Local and national policy and regulatory framework that shapes, supports or enables the facilitators in the above domains
- 14. Access to adequate funding to meet demand/need, enable quality, and invest in prevention
- 15. Any others what are they?

Questions on each of the above topics follow – one topic per page – but first.....

A. Which of the three wider-ranging factors above would you say are in most urgent need of
change/improvement to enable people with dementia to remain living well in their own
homes?

Insert numbers from the list below in the boxes. You do not need to prioritise between them.

<b>sector</b> , e regard th	ither beca nat area as	use that is particul	is where th arly in nee	ne sector co ed of attent	n make th	e most differ	by the housing ence or because you between them.

You need only answer questions on topics you know about. Please be as dementia-specific as possible in your answers.

## 1) Design of homes

What is happening in the field?

There are some generally accepted principles about designing homes for people with dementia, for example, layout, lighting, wayfinding, clarity of function, decoration, and flooring

1a) Is the knowledge about designing homes for people with dementia being applied? And is this in specialist housing, ordinary housing or both? Where possible give concrete examples.
1b) What are the current issues, gaps or barriers in implementing dementia design principles in new homes or existing homes? Please differentiate between specialist and ordinary housing. Where possible give concrete examples.
Possible solutions
1c) Have you had any successes in addressing these issues or barriers? Do you have any ideas about how these issues or barriers should be addressed and by whom? And is there anything in particular the housing sector could do?
Case studies
1d) Are you able to supply a case study that illustrates any of your answers?
Yes No

# 2) Maintenance, repairs, aids and adaptations in both ordinary and specialist housing

Maintenance refers to keeping the property in good order, for example by decorating. Repairs restore items to a good condition and include minor and major works such as roof repairs and renovation work to windows. Aids might range from simple equipment such as white boards and key safes to hoists. Adaptations refer to structural changes to the property such as level access showers, adapted kitchens and handrails. Some aids and adaptations are specifically designed for people with dementia, for example dementia-friendly showers and toilets.

2a) How are repairs, aids and adaptations being used to help people with dementia (and

those they live with) to remain in their own home for longer? Is there evidence that these are improving outcomes for people living with dementia and their carers? Where possible give concrete examples.
2b) Are their gaps in aids and adaptations specifically designed for people with dementia? What are the current issues or barriers for people with dementia and their carers in accessing aids or adaptations? Where possible give concrete examples.
Possible solutions
2c) Have you had any successes in addressing these issues? Do you have any ideas about how these gaps or barriers should be addressed and by whom? And is there anything in particular the housing sector could do?
Case studies
2d) Are you able to supply a case study that illustrates any of your answers?
Yes No

If yes and it is already available please attach or supply link

What is happening in the field?

## 3) Assistive Technology

This category refers main to electronic technology. Whilst not suitable for everyone, technology solutions can work in a variety of ways to support health, safety and communication, manage risks, provide enjoyable and stimulating activities and support loved ones. Examples include:

- a familiar gadget such as a mobile phone/TV
- a specific telecare device to remind someone to take medication, movement sensors or location devices
- an app to enable social interactions or memory stimulation
- technology which supports cognitive stimulation, leisure and social engagement
- telehealth to enable health conditions to be monitored from home.

## What is happening in the field?

3a) To what extent is assistive technology being used to help people with dementia to remain living well and safely in their own homes and what types of AT are they? Where possible give concrete examples.
3b) Are their gaps in assistive technology specifically designed for people with dementia? What are the current issues or barriers for people with dementia and their carers accessing technological solutions? Where possible give concrete examples.
Possible solutions
3c) Have you had any successes in addressing these issues/barriers? Do you have any ideas about how these issues or barriers should be addressed and by whom? And is there anything in particular the housing sector could do?
Case studies
3d) Are you able to supply a case study that illustrates any of your answers?
Yes

## 4) Neighbourhood design

What is happening in the field?

As with building design, there are agreed principles about neighbourhood design, for example around navigation and surfaces.

4a) To what extent is knowledge about design of neighbourhoods for people with dementia being applied? Where possible give concrete examples.
4b) What are the current issues, gaps or barriers in implementing dementia design principles when developing or re-developing neighbourhoods? Where possible give concrete examples.
Possible solutions
4c) Have you had any successes in addressing these issues/barriers? Do you have any ideas about how these issues or barriers should be addressed and by whom? And is there anything in particular the housing sector could do?
Case studies
4d) Are you able to supply a case study that illustrates any of your answers?
Yes No

## 5) Supply of suitable homes

What is happening in the field?

While this category can include specialist housing, it is also intended to refer to ordinary housing that is suitable people with dementia (see q1 page 5)

5a) Are there enough affordable homes on the market or being built where they are needed that are suitable for people with dementia? Where possible give concrete examples .
5b) What are the current issues, gaps or barriers in the supply of these homes? Where possible give concrete examples.
Possible solutions
5c) Have you had any successes in addressing these issues/barriers? Do you have any ideas about how these issues or barriers should be addressed and by whom? And is there anything in particular the housing sector could do?
Case studies
5d) Are you able to supply a case study that illustrates any of your answers?
Yes No

### 6) Access to broad-ranging information, advice and advocacy

The Care Act requires local authorities to ensure that these are available, though they are not required to provide it themselves, so that people with dementia and their carers know what options are available to them and how to access them.

What is happening in the field?
6a) Is there good access to information, advice and advo

6a) Is there good access to information, advice and advocacy both at a national and local level that enable people with dementia and their carers to make informed choices about where they live and what form their support should take? Is it accessible to people from diverse communities? Who provides these services? Where possible give concrete examples.
6b) What are the current issues, gaps or barriers in the supply of these services? Where possible give concrete examples.
Possible solutions
6c) Have you had any successes in addressing these issues/barriers? Do you have any ideas about how these issues or barriers should be addressed and by whom? And is there anything in particular the housing sector could do?
Case studies
6d) Are you able to supply a case study that illustrates any of your answers?
Yes No

# 7) Access to practical help and informal support networks, for example friends, family and neighbours

While this inevitably varies between individuals, such support is a vital part of supporting people with dementia and their carers. Service providers may play a part in facilitating or promoting this. People with dementia from black and minority ethnic groups and other minority groups may face particular challenges.

7a) What current initiatives are in place that can help individuals with dementia and their carers, including those from groups with protected characteristics, to maximise the support they receive from informal support networks? Where possible give concrete examples.
7b) What are the current issues, gaps or barriers in accessing informal support? Are there particular challenges faced by people from groups with protected characteristics? Where possible give concrete examples.
Possible solutions
7c) Have you had any successes in addressing these issues/barriers? Do you have any ideas

about how these issues or barriers should be addressed and by whom? And is there anything

#### **Case studies**

7d) Are you able to supply a case study that illustrates any of your answers?

Yes		No	

in particular the housing sector could do?

What is happening in the field?

## 8) Inclusion and absence of stigma – an informed public and dementia-friendly communities

What is happening in the field?

The attitudes of other people to those living with dementia play a significant part in enabling people to feel safe and valued in their own homes and communities, or to feel vulnerable and isolated.

8a) What current initiatives are in place to i) ensure people with dementia and their carers from diverse communities have a voice as citizens and ii) reduce stigma and make the communities within they live dementia-friendly? Where possible give concrete examples.
8b) What are the current issues, gaps or barriers in promoting inclusion and eradicating stigma across society, including people from black and ethnic minority as well as lesbian, gay, bisexual and transgender communities? Where possible give concrete examples.
Possible solutions
8c) Have you had any successes in addressing these issues/barriers? Do you have any ideas about how these issues or barriers should be addressed and by whom? And is there anything in particular the housing sector could do?
Case studies
8d) Are you able to supply a case study that illustrates any of your answers?
Yes No

# 9) Access to support services for person with dementia and family carers whether from the voluntary, social care, health or housing-related sectors

In addition to informal support, people with dementia and their carers are likely to need support from more formal universally available or specialist services at various points through their journey with dementia. These might be individual or group-based services such as peer support.

What is	hap	pening	in the	field?
TT IIGE IS	HUP	PCIIII	,	iicia.

9a) Are people with dementia and their carers able to access the support they need, in the form they want it when they need it? What initiatives are in place to make this a reality? Are the services tailored to cultural, ethnic, faith or other special characteristics? Where possible give concrete examples.
9b) What are the current issues, gaps or barriers in accessing tailored support services? Where possible give concrete examples.
Possible solutions  9c) Have you had any successes in addressing these issues/barriers? Do you have any ideas about how these issues or barriers should be addressed and by whom? And is there anything in particular the housing sector could do?
in particular the housing sector could do:
Case studies
9d) Are you able to supply a case study that illustrates any of your answers?
Yes No

# 10) Integrated working across sectors, disciplines, services and policies, shaped around the person with dementia and their family carers

Families want different services to work together for the individual to enable cohesive, integrated and personalised assessment and support

10a) Is there effective integrated working "on the ground" across sectors, in particular between housing, health and social care? Where possible give concrete examples.
10b) What are the current issues, gaps or barriers to joint working? Where possible give concrete examples.
Possible solutions
10c) Have you had any successes in addressing these issues/barriers? Do you have any ideas about how these issues or barriers should be addressed and by whom? And is there anything in particular the housing sector could do?
Case studies
10d) Are you able to supply a case study that illustrates any of your answers?
Yes No

If yes and it is already available please attach or supply link

What is happening in the field?

# 11) Dementia-friendly organisations in particular housing organisations

What is happening in the field?

People with dementia who are housed by, or receive services from, housing organisations are likely to be able to remain in their own homes for longer if the organisation's ethos, policies, procedures, practice and training are dementia-friendly

11a) What are housing organisations doing to become more aware of dementia and more dementia-friendly? Where possible give concrete examples
11b) What are the current issues, gaps or barriers to becoming dementia-friendly organisations? Where possible give concrete examples.
Possible solutions
11c) Have you had any successes in addressing these issues/barriers? Do you have any ideas about how these issues or barriers should be addressed and by whom? And what in particular could the housing sector do?
Case studies
11d) Are you able to supply a case study that illustrates any of your answers?
Yes No

## 12) Well-informed, aware and skilled workforce across all sectors and industries, and in particular in the housing sector

Everybody, including employees, Board, contractors and volunteers working for an organisation whose customers may have or develop dementia need awareness, knowledge and skills appropriate to their particular role

12a) What are housing organisations doing to ensure this wide range of personnel have the necessary knowledge and skills to work sensitively and effectively with people living with dementia? Where possible give concrete examples
12b) What are the current issues, gaps or barriers in skilling their staff and Board members? Where possible give concrete examples.
Possible solutions
12c) Have you had any successes in addressing these issues/barriers? Do you have any ideas about how these issues or barriers should be addressed and by whom? And what in particular could the housing sector do?
Case studies
12d) Are you able to supply a case study that illustrates any of your answers?

If yes and it is already available please attach or supply link

No

Yes

What is happening in the field?

# 13) Local and national policy and regulatory framework that shapes, supports or enables the facilitators in the previous topics

These may range from social policy and welfare benefit regulations to planning and building regulations

What is happening in the field?

13a) What policies and regulations play a part in enabling people with dementia to remain in their own homes if they choose to? Where possible give concrete examples
13b) What are the current issues, gaps or barriers either in the policies and regulations themselves or in the way they are being implemented or interpreted "on the ground"? Where possible give concrete examples.
Possible solutions
13c) Have you had any successes in addressing these issues/barriers? Do you have any ideas about how these issues or barriers should be addressed and by whom? And is there anything in particular the housing sector could do?
Case studies
13d) Are you able to supply a case study that illustrates any of your answers?
Yes No

# 14) Access to adequate funding to meet demand/need, enable quality and invest in prevention

### What is happening in the field?

14a) Are sources of funding available to adequately meet demand for good quality services that support carers and enable people with dementia to live well at home, as well as preventing them from moving to a more structured setting if they prefer to stay where they are? Where possible give concrete examples.
14b) What are the current issues, gaps or barriers in access to funding? Where possible give concrete examples.
Possible solutions
14c) Have you had any successes in addressing these issues/barriers? Do you have any ideas about how these issues or barriers should be addressed and by whom? And is there anything in particular the housing sector could do?
Case studies
14d) Are you able to supply a case study that illustrates any of your answers?
Yes No

15) Are there other important factors which can facilitate or act as a barrier to people with dementia remaining in their own homes? What are they?
What is happening in the field?
15a) What else is happening "on the ground" in relation to these factors? Where possible give concrete examples
15b) What are the current issues, gaps or barriers in these areas? Where possible give concrete examples.
Possible solutions
15c) Have you had any successes in addressing these issues/barriers? Do you have any ideas about how these issues or barriers should be addressed and by whom? And is there anything in particular the housing sector could do?
Case studies  15d) Are you able to supply a case study that illustrates any of your answers?
Yes No

If yes and it is already available please attach or supply link

Thank you for completing this survey. Please save your answers and rename the file with your or your organisation's name on it and send it to <a href="mailto:sue@suegarwood.co.uk">sue@suegarwood.co.uk</a> by end of Tuesday 13<sup>th</sup> December.

### H | D | R | C

# Housing and Dementia Research Consortium Priority Research Themes

### 1. Advantages and disadvantages of different models of Housing with Care schemes for people living with dementia.

- What different models of Housing with Care (integrated, separated, specialist, hybrid, other) exist for people living with dementia?
- What, if any, are the differences between the different models in terms of quality of life and outcomes for people with dementia and their carers?
- Integration vs segregation.
- Does the stage of dementia on moving in affect the outcomes?
- What is the role of background support?
- What are the optimum staffing ratios for each model?

### 2. The effect of building and environment on outcomes for people living with dementia.

- There is a lot of anecdotal evidence, this needs to be formalised and the learning applied to different settings.
- What really works; what are the key design features that impact on people living with dementia and the ability to support them effectively?
- What are the challenges of designing for people living with dementia?
- What does the Housing with Care building design specification offer as compared to sheltered housing, general needs housing and other types of accommodation?
- What is the optimum size for a Housing with Care setting?
- What are the effects of different building management systems (e.g. telecare, alarms) for residents living with dementia?
- Do the principles for dementia-friendly environments in care homes also apply to Housing with Care?
- Could there be some form of kite-marking?

### 2a Impact of interaction with the outside community.

 What is the impact of interaction with the outside local community on the health and wellbeing of residents living with dementia in extra care / continuing care settings?

Dr Julie Barrett HDRC 2016

- The impact of residents going out into the local community as well as the local community coming into the scheme.
- What is the impact on members of the local community who use the shared facilities?
   What is the effect on their understanding of and attitudes towards people living with dementia?
- What are the benefits of a community hub and how best to make the most of the opportunities it affords?
- What are the optimal arrangements around communal facilities inclusive of the needs of people living with dementia?
- The effect of location (urban, suburban, rural).

#### 2b Green Dementia Care.

- What is the impact of interaction with nature on multiple health and wellbeing dimensions for people with mild cognitive impairment / early stage dementia living in different accommodation settings?
- 3. Suitability of Housing with Care as compared to other forms of housing for people living with dementia and home-for-life issues.
- What are the issues influencing decisions of people living with dementia and their carers to move into Housing with Care? How do people make the choice to move into Housing with Care, as opposed to other forms of housing or staying their own home? How is the decision made for people to move into, or from, Housing with Care? Who makes the decisions? What role do factors such as capacity to give consent and deprivation of liberty play?
- Does moving to Housing with Care lead to positive outcomes, such as meeting expectations and previously unmet needs, improving health and wellbeing and enabling residents living with dementia to lead active lives?
- When and why is Housing with Care indicated as opposed to residential care?
- At the point of entry to Housing with Care, is housing with care a suitable option for everyone, at all stages of dementia to move to, and if not, what are the criteria for determining that Housing with Care is an unsuitable option?
- For people already living there, as dementia progresses, does Housing with Care continue to be suitable? Under what circumstances does Housing with Care become unsuitable for an occupant with dementia? What criteria are, and should be, used to determine when this point has been reached, and what can be done to minimise the number of avoidable moves to alternative settings?

 What role does supported housing take in the journey of people from early to late stage dementia e.g. reduction of hospital admissions?

#### 4. Use of assistive technology.

- How useful, acceptable and effective are various assistive technology devices in supported housing a) for occupants living with dementia, b) for families, staff and management?
- Could we be smarter about how we use assistive technology (e.g. interaction with people through technology, flexible packages)?

### 5. The effect of personal budgets.

- In the context of personal budgets, what will be the impact of care and support
  procurement models, and service configuration and delivery, on the wellbeing of people
  with dementia living in Housing with Care?
- Changes from block funded schemes and contracts for those with dementia: what are the differences in contracting and what is the effect?
- What are the barriers and enablers to personalisation and to providing the necessary levels and flexibility of care in response to this group and increasing care and support needs?
- For occupants living with dementia, to what extent are these mechanisms maximising choice and control within the context of the individual's capacity and wish to exercise them, and what are the outcomes for the individual?
- Why have personal budgets not been taken up by people with dementia?

### 6. Cost effectiveness of Housing with Care for people living with dementia compared to other living situations.

- Is Housing with Care a cost-effective accommodation and care option for people living with dementia and how does it compare with other living situations in terms of costs to all stakeholders, the older person's journey and quality of life outcomes?
- Are there opportunities to use data already collected by the NHS in terms of how often people are admitted to hospital and collate this with their living situation?

### 7. Effective understanding of and communication with people at all stages of dementia.

How to understand the needs and feelings of people living with dementia e.g. what they
are trying to tell us.

- How best to assess their quality of life.
- How to communicate effectively with people living with dementia.

### 8. Views of people with dementia living in different accommodation and care settings.

- What are the post occupancy views of people living with dementia living in different accommodation and care settings?
- How do residents who do not have dementia feel about those that do?

### 9. Maximising wellbeing – voice, choice and control for people living with dementia living in different accommodation settings.

- How do staff ensure that people living with dementia have their voices heard and are empowered to engage with the community and exercise choice and control as far as possible so that they feel they belong and experience high levels of wellbeing?
- How do staff balance risk taking, autonomy and self-determination with protecting individuals from harm, and if someone needs to be deprived of their liberty in their own best interests, what steps are being taken?

### 10. Easing the transition from home into housing and care settings and settling in.

- How to make the transition from home into a supported living / care setting easier for people living with dementia
- How best to help people living with dementia to maintain their independence while effectively supporting their needs and helping them to settle in.

The first two research themes were considered by HDRC members to be the first and second most important research themes, the remaining themes are in no particular order. Priorities 7 and 8, being themes that would add value to a proposal, need to underpin all of the other research themes. Seeking the views of people with dementia using appropriate methods of understanding and communication must be incorporated into every research project that the HDRC is involved in.

#### 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 endof-life care

The DHWG is currently chaired by Homeless Link. For more information on the DHWG see: <a href="https://www.housinglin.org.uk/housing-networks/dementia-and-housing-working-group">https://www.housinglin.org.uk/housing-networks/dementia-and-housing-working-group</a>

#### 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: <a href="https://www.housinglin.org.uk/Dementia">www.housinglin.org.uk/Dementia</a>

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