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HOUSING AND
CARE FOR
OLDER PEOPLE

Housing for people with dementia – are we ready?

A report from an Inquiry by
the APPG on Housing and
Care for Older People

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February 2021





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Lord Best
OBE Co-chair,
All Party Parliamentary
Group on Housing and
Care for Older People

Inquiry Chair's Foreword

There are no vaccines for dementia. One in 14 of us aged over 65, and one in 6 of us aged over 80, will find ourselves living with dementia. There is currently no cure, and in most cases the condition worsens over time.

Housing - where we live, where we spend nearly all our time - is a critical element in addressing this predicament. *'Every care decision is a housing decision'*, as one of our expert witnesses told us. Get the housing right and life with dementia can be eased; a move into residential care can be avoided or postponed, and places in hard-pressed care homes kept available for others who really need them.

Our Inquiry - established by the All Party Parliamentary Group on Housing and Care for Older People which is chaired by Peter Aldous MP, and myself - has benefitted hugely from the input of those with personal experience of dementia and from the key professionals working in this field. These contributors have helped us Parliamentarians to realise that although every individual's needs are different, there are positive ways to address the housing requirements which dementia raises.

Of course, central and local government are powerful players in helping us get ready. So are the providers of new homes and care services. It is clear that the nation must greatly increase production of suitable new homes and the retrofitting of existing accommodation.

But all of us have our own part to play. We need to ask ourselves 'If dementia comes our way, are we ready? Will our home serve us well? Will it be somewhere we can continue our lives together or alone?'

For some of us, adaptations to our existing home will be the answer. For others, 'right-sizing' to accommodation that can meet whatever needs we have, will be the sensible option. 'Good older person design is good dementia design' as the Inquiry was told.

The COVID pandemic has shown us the importance of sustaining connections and avoiding loneliness and isolation. Do we need a place to live where social contact can be maintained, companionship found, and a social life made easy? Do we need to have care and support close at hand to sustain our own independence?

Whatever steps we consider, access to good advice is paramount.

This report makes recommendations for all the key players, with an overarching message: joining together housing and care is key. As politicians and practitioners and citizens, we all have a part to play in getting ready so that everyone with dementia, now and in the future, can lead fulfilling lives.

Richard Best
February 2021

Acknowledgements



Image Credit: Anchor Hanover

This APPG inquiry would not have been possible without the tremendous support of Anchor Hanover. Panel members also wish to thank Jeremy Porteus, Chief Executive of the Housing LIN (Learning and Improvement Network) and Katey Twyford, Dementia Co-lead for the Housing LIN, for planning the Inquiry sessions and pulling together the oral and written evidence submitted into this impressive report, Lois Beech, Senior Research Officer at the Housing LIN, and Kennedy Williams and Madeleine Harding, interns to Lord Best, for their administrative support.

We are also grateful to those organisations who supplied images for inclusion. Please note, all people shown on this report do not necessarily have dementia.

Executive summary



Image Credit: Guinness Partnership

The Inquiry set out to explore the policy changes needed to help people live as well as possible with dementia in their own homes – from mainstream housing to specialist provision such as Extra Care Housing or Assisted Living schemes.

Against a backdrop of the escalation of Covid-19, four Inquiry sessions were held virtually between June and December 2020. They sought expert evidence on:

- The lived experience of people with dementia
- The links between housing, health, and social care to improve the journey of someone affected by dementia
- The design of new homes
- Ways to increase supply of specialist dementia-friendly properties
- Changes and adaptations to existing homes to enable people to live well with dementia, and
- The role of innovative technology to improve the delivery of better care and support.

The Inquiry sought evidence on all aspects of housing with care for older people with dementia, but did not include residential care or nursing homes.

What we found - key issues:

There is an urgent need to ensure that housing is 'dementia-ready' from the outset. While we found some excellent examples of housing organisations that have developed dementia-friendly strategies or signed up to become 'dementia friends', across the whole sector progress has been slow. Our Inquiry heard, if we do not address this now, we will continue to build housing that doesn't anticipate the care and support needs of this and future generations of people living with dementia.

It was also pointed out that the majority of adults living with dementia do not live in purpose-designed housing. Dementia affects both the person living with dementia and people who are undertaking a caring role such as a spouse or partner a son or daughter or sometimes a friend or other relative. While many people live with carers, a growing percentage of people live alone. The health and wellbeing of both the person living with dementia and their carers is important. The relationships that people with dementia have are as diverse as the people themselves, some may have no carers in any formal sense and others may have a network of people that they draw upon at different times.

We therefore must take action to enable people affected by dementia to access the best advice and support to adapt their environment to live as well as possible or identify accommodation and services that better meet their specific needs. With prevalence of dementia on the rise in the UK, this can be done now if we all adopt a dementia inclusive approach.

Twenty key issues arose during the Inquiry:



Image Credit: Idratek Ltd

Health and wellbeing

- **Key Issue 1:** Dementia-ready housing can be comfortable and stylish and should aim to enable people to remain independent for as long as possible; maintain relationships with family and friends; enable people to be part of a community; prevent avoidable hospital admissions; and delay admission to a long term care setting. Housing has a significant impact on carer wellbeing.
- **Key Issue 2:** Dementia Care Pathways do not usually link care and housing together. Health and care assessments, particularly at the post-diagnostic stage, should take into account the extent to which a person's accommodation is dementia-ready.

Information and advice

- **Key Issue 3:** People living with dementia and their carers do not always receive sufficient information and advice about housing implications at the point when they suspect or receive a diagnosis of dementia.
- **Key issue 4:** The timeliness of post-diagnostic support and advice is crucial. This is a time when all those affected need to find solutions together, and agree next steps. Staff supporting people at this stage should feel confident to have these discussions with the person.

Housing Supply

- **Key Issue 5:** There is evidence that living in specialist housing for older people can reduce costs to NHS and Social Care budgets, but there remains a projected shortfall of housing for older people by 2030, including those that can accommodate people living with dementia.
- **Key Issue 6:** Most people with dementia continue to live in ordinary homes with only a minority of people living in specialist housing. A lot of ordinary homes require significant investment to bring them up to date and adapt them to support people living with a variety of needs, including dementia.

Adaptations and home improvements

- **Key Issue 7:** Many people living with dementia are home-owners but have limited resources to fund improvements to their homes. They require the support of Disability Facility Grants and other local funds such as the Dementia Dwelling Grant.
- **Key Issue 8:** Barriers to home improvements for people with dementia include lack of knowledge of what is possible and the challenge of organising the necessary building works. Disabled Facilities Grants are in short supply or not easily available in some areas, and the system can be difficult and slow to access.
- **Key Issue 9:** Home Improvement Agencies (HIA) and Occupational Therapists play a vital role in supporting people to navigate the complexities of the grants system, to access appropriate technical advice and to manage building work to make homes dementia-ready. Access to HIAs or Occupational Therapists can be variable across the country.

Design for homes and communities

- **Key Issue 10:** As championed in the HAPPI reports, well-designed housing is good for everyone. There is currently no single agreed set of dementia design principles in use to help make new homes ready for occupants who may live with dementia now or in the future. When looking at design some of the biggest impacts come from things that are easy to change and not necessarily expensive.



- **Key Issue 11:** Too often good design for those living with dementia is compromised because of lack of understanding by town planners, architects, designers, building control officers, constructors, and developers. This can impede the development of dementia-ready housing and dementia friendly communities.

Housing and care management

- **Key Issue 12:** There is a problem with the private rented sector (PRS) being prepared to support people with dementia as their needs change. Some private landlords are reluctant to invest in properties to make them dementia-ready either due to negative perceptions about dementia or because of concerns the tenant may not be there for long. The social sector needs to grow and provide more dementia-ready and adapted housing alongside new build in the private sector.
- **Key Issue 13:** The restrictions imposed in response to Covid-19 have highlighted existing challenges to housing providers. Many people affected by dementia have reported deterioration of their condition, but also an increased reticence to move to a care or nursing home. Creative solutions have been adopted by housing providers, often as a result of the property services, housing management and care teams working together. These examples of best practice need to be shared across the sectors.



Image Credit: Glancy Nicholls Architects

Assistive technology

- **Key Issue 14:** Technology can improve and complement the effectiveness of support systems for the person. The use of mainstream devices, the internet, telephone and/or mobile technology can help if it is adopted early, and is being used increasingly by people living with dementia to support daily living and maintain social connections.
- **Key Issue 15:** Use of technology can be an issue in some rural areas where there is limited digital coverage.

Workforce

- **Key Issue 16:** The workforce that supports general and specialist housing for older people is varied and dispersed. Providing and targeting good quality training to ensure that this workforce has adequate knowledge, skills, and attitudes to support people with dementia and their carers is challenging. There is a gap in training and education for family and informal carers.
- **Key Issue 17:** The workforce needs skills to enable people to live their lives in a way that enhances their independence and manages risk in a proportionate way over time. Premature removal of risks can be detrimental to a person's wellbeing.

Legislation

- **Key Issue 18:** People living with dementia sometimes experience difficulty obtaining a tenancy for housing where it is believed they do not have the mental capacity to either sign or manage it. This requires attention and legislative clarity.

Research

- **Key Issue 19:** The impacts of housing, home adaptations, workforce skills, and ways of delivering interventions and technology to support people living with dementia are under researched in the UK. Universities are starting to engage with research in these fields but research funding that specifies dementia and housing as a topic will encourage this further.



Image Credit: Johnnie Johnson Housing/Astraline

- **Key Issue 20:** There should be a greater focus on collecting relevant data in the wide range of housing surveys undertaken. For example, by the inclusion of more dementia specific questions to inform national policy development and aid service improvement.

Getting ready for dementia – a summary of recommendations



Credit: Belong Ltd

The Inquiry heard about the housing and care experiences of older people living with dementia and their carers. It then heard about the importance of planning for well-designed dementia-ready housing and how the planners, architects, developers, commissioners, and landlords all have a role to play. The Inquiry heard how people live better when their housing is integral to the local community.

There is a recognition that most people with dementia live in housing that was not purpose built to be dementia-ready. The Inquiry heard how technology, aids and adaptations can help or hinder someone with dementia to live well and makes recommendations to improve the wellbeing of individuals by working with them to harness technology and adapt the environment. Crucially, the Inquiry heard that “*every decision about care is a decision about housing*” and we make recommendations to optimise the costs and benefits of an integrated approach to housing and care decisions. A summary of the recommendations is set out below for each of the following groups:

- All of us
- Cabinet Office
- Department of Health and Social Care and NHS
- Ministry of Housing, Communities, and Local Government

- Department for Business, Energy, and Industrial Strategy:
- Local Authorities (Adult Social Care, Housing Services and Planning)
- Providers of housing for older people in the private and social sectors
- Technology manufacturers and suppliers of platforms and portals, including social media
- Others involved in housing provision

To ensure dementia readiness:-

We recommend that we all:

1. Recognise potential future loneliness and how we can maintain our family connections and wider social networks in the communities we live in before or after a diagnosis of dementia.
2. Consider whether to move whilst we are able: right sizing and moving to the right place or environment whilst able to still develop new routines and make new friends.
3. Make preventive changes, incrementally, to the home environment; such as when upgrading property or installing new technology, or where we require additional personal care and support to help us to live independently.



Image Credit: Glancy Nicholls Architects

We recommend that the Cabinet Office:

4. Brings together the Department for Health and Social Care (DHSC) with NHS England, the Ministry of Housing, Communities and Local Government (MHCLG) and HM Treasury to forge an overarching strategy for housing and care for older people, with the needs of those living with dementia as a core component.
5. Establishes a Cabinet lead role/Minister for Ageing with responsibility across MHCLG, DHSC and other government departments for issues of housing and care, including dementia.
6. Devises a new national outcome measure that reflects the quality of life of those living with dementia (diagnosed or pre-diagnosis), to drive a focus on partnership for housing, health, and social care, and to deliver improvements in wellbeing outcomes.

We recommend that the Department of Health and Social Care and NHS:

7. Recognise the interdependency between housing, social care and the NHS in supporting people with dementia and correspondingly rethink funding to prevent the need for higher-cost services.
8. Support enhanced coordination of GP/CCG or Primary Care Network services, both with local authority Adult Care Services and with local authority Housing Departments/social housing providers, to deliver joined up housing and care services that are dementia-inclusive.
9. Stimulate a shared approach across the health-care-housing sectors and share information more effectively to break the barriers between sectors where those with dementia become lost to the system. Reduce the stigma of dementia, facilitate timely diagnosis, and ensure that the post diagnostic pathway is set up to help people make decisions about their housing options.
10. Seek to ensure that advice and information is available through NHS and other portals to those living with dementia, and their carers and families, incorporates guidance on benefits and housing options. This will include web-based sources of information as well as more traditional information sources, and could be provided by third sector organisations.

11. Draw on lessons from local community ‘hubs’ and provide further investment in specialist dementia nurses such as Admiral nurses, care navigators, dementia advisers and other specialist dementia roles across housing and social care in the community, including within extra care housing settings.



Image Credit: Glancy Nicholls Architects

12. Commission research, as part of the NHS digital strategy, into the effective use of technology to enable people with dementia to live in their homes and prevent or delay a costly move to a more formal care setting.
13. Strengthen the DHSC’s Care and Support Specialised Housing Fund Prospectus to take on board the conclusions and recommendations of this report.

We recommend that the Ministry of Housing, Communities, and Local Government:

14. Support increased provision of Extra Care Housing/ Assisted Living accommodation and retirement housing that is dementia-ready, with top-sliced grant-aid through Homes England and the GLA Affordable Homes Programme.
15. Strengthen MHCLG guidance to local planning authorities, following the recent Planning White Paper and proposed changes to the National Planning Policy Framework. Local planning authorities should respond to demographic change and the need for more homes designed for older people, including those with dementia, through Local Plans specifying requirements for age-friendly housing.

16. Amend the Building Regulations following the recent consultation on accessible design and the proposal for a national model design code, to require the Lifetime Homes accessibility standards encompassed in Part M4(2) for all future house building.
17. Increase further the level and flexibility of Disabled Facilities Grants (DFG) and help through Better Care funding, to ensure these can be deployed to address home improvements and adaptations that meet the individual needs of those living with dementia.
18. Promote more widespread adoption of Dementia Dwelling Grants and the role of Home Improvement Agencies / Care and Repair Agencies, and Occupational Therapists, in supporting older and disabled people, including households with someone with dementia.



Image Credit: Oxford City Council Home Improvement Agency

We recommend that the Department for Business, Energy and Industrial Strategy (BEIS):

19. Draws out key lessons from the United Kingdom Research and Innovation Challenge accelerator projects incorporating housing for those living with dementia and disseminates widely through its programme.
20. Makes available funding for innovation to mainstream dementia ready design and technology e.g. for national retailers and manufacturers including makers of equipment and personal devices such as GPS trackers and 'Fitbits'.

We recommend that Local Authorities (Adult Social Care, Housing Services, and Planning):

21. Ensure provision of independent housing information and advice to give people who receive a diagnosis of dementia – and their families and carers - guidance on future housing options for 'right-sizing', moving to specialist accommodation, adapting their home, making small but impactful changes to the environment etc.
22. Through their planning departments, identify, in their Local Plans, clear requirements for older people's housing, including those from minority communities. Specify a proportion of the homes in all major developments that should meet these needs, as well as allocating 'suitable sites' (e.g. in town centres), identified in conjunction with local housing and care providers specifically for age-friendly housing.
23. When producing their housing plans, as set out in the government's National Statement of Expectations for Supported Housing, councils should identify the shortfall of new purpose-built housing for older people, such as extra care housing. Plans should set out the housing demand for people living with dementia in their locality including estimates for need among BAME and LGBT communities and how these will be met.



Image Credit: Peter Kindersley/Centre for Ageing Better

24. Specify in Local Plans their requirements on accessibility for all new housing in their area and set out specific criteria that incorporates dementia-ready housing. Notwithstanding the outcome of the current consultation on Accessible Standards, require new homes to be built to the Part M4(2) standards and / or Lifetime Homes to prevent crises that would otherwise require high cost healthcare.
 25. Through their housing departments, recognise the growing demand for age-friendly and dementia-ready social rented housing for those currently living with dementia in unsuitable private rented homes.
 26. Where the authority is developing extra care housing or retirement housing apply HAPPI design principles and the specific guidance on dementia design in this report and sign up to the dementia-friendly housing charter.
 27. Through their Adult Social Care departments, devise care strategies that include the housing dimension, whether through new homes or home adaptations and transformative technology, to support the occupiers and their informal and formal carers. The aim should be to prevent or postpone the need for more care in the home or a move into a residential care setting.
 28. Extend the service of Home Improvement agencies to manage the complexities of the grants system, access appropriate technical advice and help to manage the building work to make their home dementia-ready and improve the provision of independent home adaptations and handyperson services to secure the adaptations that could be of most help.
 29. Ensure the Local Authority's housing workforce is competent in the Dementia Standards Training Framework at a level appropriate to their role.
 30. Undertake holistic needs assessment and joint case management with housing providers, under the Care Act 2014, for allocating homes and supporting transfers of care from acute hospital settings back home or to dementia-ready accommodation.
 31. Seek practical solutions, of which technology may be a component, using the expertise of people affected by dementia to tailor solutions to each individual. Get the buy in of a wide range of stakeholders including family, carers, landlords, social services, and police.
 32. Ensure the voices of older people, including those affected by dementia, and their carers, are heard within the decision-making processes of the Local Authority.
 33. Work with households with lived experience of dementia, community groups, housing providers, and other partners in their area to implement the Alzheimer's Society dementia friendly housing guide and support the development of dementia-friendly neighbourhoods.
- We recommend that providers of housing for older people in the private and social sectors:**
34. Consider the design and adaptability of their homes in meeting the needs of those living with dementia, covering both 'hard design' (wider doorways, accessible kitchens and bathrooms that enable independence) and 'soft design' (covering the auditory impact of surfaces, the use of tactile and visual cues as reminders, sign-posting, labelling).
 35. Appoint dementia 'champions' at executive / senior management / board level, in general needs social and specialist housing bodies, to demonstrate organisational commitment and ensure effective leadership at the highest level.
 36. Utilise the Alzheimer's Society's dementia-friendly housing guide or other recognised guide, and actively promote their dementia readiness, including producing relevant information for their customers and signposting where they can access advice.
 37. Make sure that lease and tenancy agreements are accessible to people living with dementia and / or their legal representatives including those with Power of Attorney.
 38. Ensure that those providing care and support for people living with dementia sign up to be dementia 'friends' and have appropriate training and supervision to respond to complex needs. Staff need strong values, a good understanding of dementia, and self-awareness, along with specific skills such as communication and managing risk. The housing workforce should be familiar with the Dementia Standards Training Framework and be able to demonstrate how they meet the standards within it appropriate to their role.
 39. Give the necessary priority in the allocation of available social housing to those living with dementia, bearing in mind the progressive nature of the condition.
 40. Sign up to a dedicated learning and information network to receive and share best practice on housing and dementia.

We recommend that technology manufacturers and suppliers of platforms and portals, including social media:

41. Make their mainstream technology systems usable for people with dementia and their carers, and provide access to easy to follow advice and support so that mainstream technology can be adopted and used effectively as a person's dementia progresses.
42. Have regard to the publications of the Alzheimer's Society on Dementia Friendly Technology.



Image Credit: Oxford City Council Home Improvement Agency

We recommend that others involved in housing provision

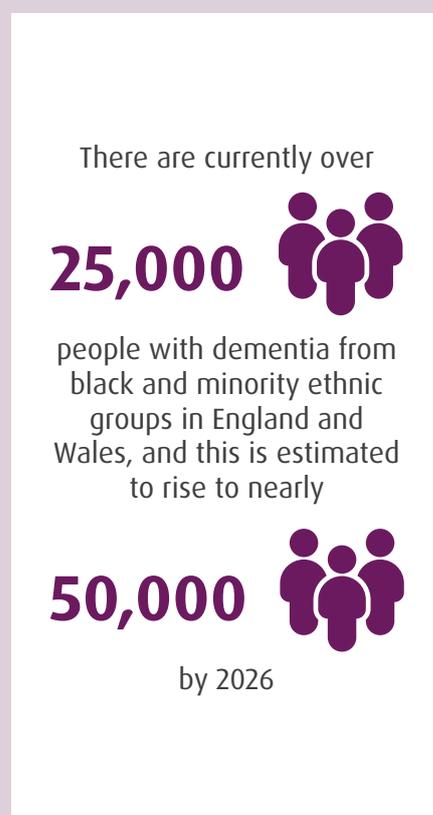
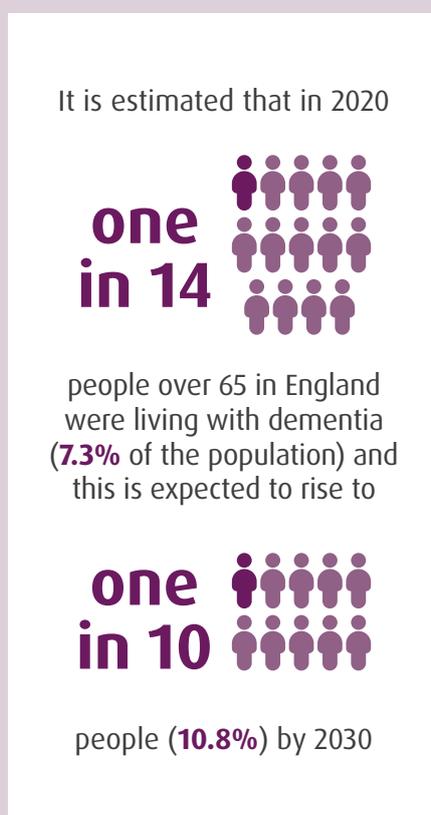
(Including developers, housebuilders, surveyors, architects, designers, and associated trades):

43. Incorporate design and technology features set out in the new dementia-ready HAPPI design principles (See Appendix 3, pp48-49) within all new purpose-built housing for older people. Adopt the M4(2) requirement in Building Regulations as a minimum standard.
44. Ensure those involved in designing and constructing new homes, and in adapting, refurbishing, or improving housing for older people, receive appropriate training in creating dementia-ready homes and dementia friendly communities.

Infographics

In this section, we pull out a number of the key facts and figures collated during this Inquiry and referenced in this report.

Demographics



Dementia and COVID-19



Carers, health and social care

Dementia cost the UK economy about

 **£35 billion**

in 2019 – more than cancer and heart disease combined. Social care accounts for 45% of these costs and 40% is from unpaid care



of people in care homes have dementia or severe cognitive impairments



of people in receipt of home care are living with dementia

There are

1.8 million 

carers of people with dementia



of people over 75 who are admitted to acute hospital are diagnosed with dementia but only half have a previous diagnosis

Of all short stay hospital emergency admissions



were of people with dementia aged over 65

Mainstream and specialist housing

Of all people living in extra care housing,



of residents are reported to live with diagnosed dementia or suspected but undiagnosed dementia.

Nearly

500,000 

(or **61%**) people with dementia live in the community in a range of different housing types. Most live in mainstream housing, with a third living on their own.

There are around

428 

Dementia Friendly Communities in England and Wales in 2020



Only **11.5%** local authorities mention dementia in their housing assistance policies

Introduction



Image Credit: Anchor Hanover

The All Party Parliamentary Group (APPG) on Housing and Care for Older People, jointly chaired by Lord Best and Peter Aldous MP, launched a six month Inquiry in June 2020 to look in-depth at key elements that will help adults with dementia to live as well as they can in a range of housing types, including housing with care schemes.

The APPG Inquiry, chaired by Lord Best, brought together a group of Parliamentarians and Panellists (see Appendix 1, p46 for list) and held four virtual sessions to hear and evaluate evidence from expert speakers on a range of topics. The APPG Inquiry Members and expert speakers included representation from previous Housing our Ageing Population (HAPPI) reports¹ and drew on the Inquiry into Decent and Accessible Homes for Older People². In addition to oral presentations, written evidence was submitted by individuals and organisations listed at the end of this report (see Appendix 2, p47).

¹ Housing our Ageing Population: Panel for Innovation (HAPPI): Available at HAPPI - Design - Topics - Resources - Housing LIN

² [appg-for-ageing-and-older-people---report-on-decent-and-accessible-homes-for-older-people.pdf](#)



We found growing evidence of the role of housing in improving health and wellbeing, reducing the need for adult social care and demand on NHS services. One in 14 people aged over 65 in the UK population are estimated to be living with dementia³, yet specialist housing for older people still represents a relatively small portion of older people’s housing.

We noted that, over ten years ago, the first HAPPI report set out a powerful argument for good design and building standards to attract people to move to better and more appropriate homes as they age. The Inquiry into Decent and Accessible Homes for Older People recommended integrating housing issues into health and care strategies and health and care issues into housing strategies including the extension of housing options available to older people and an increase in adaptations to housing stock.

More recently, the Prime Minister’s Challenge on Dementia 2020 Implementation Plan recognised the importance of housing and made a number of recommendations. For example, it stated:

“By 2020 we would like to see an increased number of people with dementia being able to live longer in their own homes when it is in their interests to do so, with a greater focus on independent living.”⁴

This new APPG Panel has gone further, focussing on the links between housing, health, and social care to improve the journey of people affected by dementia. The Panel heard from older people living with dementia about their experiences of living at home, and sought examples of best and innovative practice in the design of new homes and in changes and adaptations to existing properties to enable people to live well with dementia at home. The APPG examined ways to increase an individual’s access to specialist dementia-ready properties, and to effectively use innovative technology, aids, and adaptations to improve the delivery of care and support.

³ Whittenberg et al, Projections of older people with dementia and costs of dementia care in the United Kingdom 2019-2040 https://www.alzheimers.org.uk/sites/default/files/2019-11/cpec_report_november_2019.pdf

⁴ <https://www.gov.uk/government/publications/challenge-on-dementia-2020-implementation-plan>.

Chapter 1: What older people told us about their housing experiences and living with dementia

Most people with dementia live in the community. The current support system is predicated on many people being cared for by family and informal carers. There are a growing number of people who are ageing without children who may not have family available to be informal carers, and may be living alone. The LGBT Foundation told the Inquiry that LGBT people with dementia are less likely to have children to support them, may be more anxious about accessing services and support because of historic and current discrimination, and be more likely to be isolated due to the lack of services and support. They highlighted their work with Stonewall Housing and Manchester City Council to develop the first purpose-built LGBT extra care housing development¹.



Image Credit: Belong Ltd

¹ <http://lgbt.foundation/news/housing-ageing-and-care-what-manchester-lgbt-residents-want-from-the-uks-first-purpose-built-lgbt-extra-care-scheme/391>

They pointed out that in their housing survey 74% of responders want a home for their old age aimed at them and delivered by a LGBT-specific provider, but 43% had no idea where they would get care and support in the future.

The Inquiry also heard that there is an assumption that people from Black, Asian, and Minority Ethnic (BAME) groups look after their older relatives at home. The Abbeyfield Society told us that this is an oversimplification and the view that extended families take on responsibility for relatives with dementia should not be relied on.



Image Credit: Anchor Hanover

Furthermore, we heard that 6 out of 10 people with dementia say they experience loneliness and isolation, but not all of these lived alone². The Inquiry heard from author Wendy Mitchell, a person with experience of living with dementia, how living alone can be a positive experience, and that the decision to stay put or to move home can be a difficult one. Choices about when to move and the difficulty of developing new friendships, getting used to a new layout, and developing new routines can be hard. We learned that there is a balance to be achieved between feeling secure at home and being in a home that keeps alive memories as well as provides a sense of normality.

The Life Story Network told us about their research and how control over decisions about how and where one lives is fundamental to a sense of home and belonging³, and how they found that there is little information about housing options available to older people living with dementia and their carers.

² <http://www.alzheimers.org.uk/news/2019-05-15/lonely-future-120000-people-dementia-living-alone-set-double-next-20-years>

³ My Home Matters | Life Story Network

The Local Government Association advised that people may not need treatment or social care immediately after a diagnosis of dementia, but that they are often in a vacuum at the point when they could be making effective choices and plans to make changes to housing, care and support to meet their future needs. The Inquiry heard how professionals deliver post-diagnostic support, and learned that current assessments do not often include opportunities to explore housing matters or whether current arrangements will remain suitable as a person's dementia progresses.

People living with dementia are often living with other long term conditions and disabilities/illness including hearing and visual impairment. It was pointed out that everyone is unique, and each will find their own solutions to help them remain independent. People living with dementia described the importance of having enabling support rather than disabling support from those around them.

There are times when it is better to wait for something to happen before changing as future proofing can sometimes take away independence.

(Wendy Mitchell).

Case Study: The Fylde Coast Dementia Hub

The Fylde Coast Dementia Hub⁴ provides practical information and support for people living with, or caring for somebody with dementia, on a range of issues including recognising the symptoms of dementia and memory loss, getting help locally (such as linking in with British Legion Admiral Nurses team in North Lancashire), how to manage financially, options for staying at home and how to remain positive.

However, due to Covid, the Hubs' activities in person are on hold but the local Age UK have arranged an online dementia hub fortnightly on Friday afternoons – stakeholders, carers and people living with dementia attend.

⁴ <https://www.thefyldecoastdementiahub.org/>

"As an Admiral Nurse I provide support in the community for families in complex situations who are caring for a loved one with advanced dementia/disease. In order to reach other families in the community who aren't already under the care of the hospice, and their loved one may be at an earlier stage of dementia, I provide a signposting/advice service for local families and health professionals, via telephone. And pre-lockdown, I provided a Dementia Wellbeing group for family carers and their loved ones living with dementia at the hospice, providing education, peer support and dementia therapies."

Lorna Webber, Admiral Nurse, Trinity Hospice, Bispham

There was a strong sense of making small practical adjustments to maintain independence as well as making some of the larger scale adaptations. For example, in relation to assistive technology, we were told that early adoption of everyday smart devices such as Alexa, GPS watches etc, is essential if they are to be used effectively by individuals as their dementia progresses. The diverse experiences of living with dementia across the UK have been captured as a series of short Dementia Diaries, including how using a FitBit has motivated one person to get out⁵, and opportunities afforded to another person by technology⁶.



Image Credit: Peter Kindersley/Centre for Ageing Better

⁵ Dory is finding her new FitBit is helping motivate her to get out. - Dementia Diaries

⁶ <https://dementiadiaries.org/entry/10823/howard-talks-about-the-opportunities-afforded-by-technology>

Although access to resources can be an issue, the Local Government Association said that having access to funding doesn't help if there is a lack of timely information and advice for people about what is available. As Wendy Mitchell told the Inquiry, “*we don't know what we don't know*”.

Practice Example: Housing 21 dementia factsheets

In 2017 Housing 21 became a dementia-friendly organisation and launched an action plan to help embed their work around dementia throughout the organisation. As part of their action plan, they reference the importance of information and awareness raising in supporting their staff and residents. This includes a series of factsheets - from challenging behaviours and distressed responses to designing for dementia. They provide practical advice and tips for staff, residents, families, and other professionals⁷.



Image Credit: Housing 21

We also heard that specialist housing schemes can play a role in hosting services such as dementia memory cafes and locally based respite care which make a big difference to both people with dementia and their carers. Importantly, services like memory cafes can help share knowledge and understanding between people affected by dementia.

We learned that the cultural environment is as important as the physical environment in enabling people with dementia and people from other minority groups to live well in group housing settings.

⁷ <https://www.housing21.org.uk/about-us/our-work-with-dementia/dementia-factsheets/>

The LGBT Foundation highlighted their project, ‘Bring Dementia Out’ supported by the Guinness Partnership, to address the lack of visibility of and awareness of LGBT people living with dementia within housing with care services⁸. They stressed that housing providers must be sensitive in how they interact with people from LGBT communities, and that is it key for providers to check their basic values and embed them into the housing and care environments.

The sense of individuality and meeting everybody's needs was reflected on by the Alzheimer's Society who emphasised that “*once you have met someone with dementia you have met one person with dementia*”. Treating everyone as individuals requires equity and equality.

The Inquiry heard that the decision to move rather than adapt a house can be triggered by an inability to tackle environmental issues to help someone stay at home. Significantly, 91.8% of people living with dementia also have another health condition⁹ which can contribute to why people move home if they cannot get the right adaptations and support.

Environmental issues extend beyond the immediate home and include easy access to the neighbourhood and local community. We found that there are an increasing number of initiatives to develop dementia-friendly organisations and communities including a BSI Code of Practice¹⁰, the Dementia Friendly Housing Charter, Dementia Friendly Hospitals Charter, A Practical Guide to Becoming a Dementia Friendly Retailer, and the Dementia Friendly Garden Centre Guide. Furthermore, the recently updated Royal Town Planning Institute (RTPI) report on creating better environments for people living with dementia advises on how town planning can work with other professions to create better environments for people living with dementia. The report identifies the key characteristics of a dementia-friendly community which includes shaping communities around the views of people with dementia and their carers, appropriate transport, and easy to navigate physical environments¹¹.

⁸ <https://lgbt.foundation/bringdementiaout>

⁹ Open access report. Association of comorbidity and health service usage among patients with dementia in the UK: a population-based study | BMJ Open

¹⁰ WB12735_BSI_Dementia_ConsumerBro_AW.indd (bsigroup.com)

¹¹ Royal Town Planning Institute, Dementia and Town Planning - Creating better environments for people living with dementia, 2020. [dementiatownplanningpracticeadvice2020.pdf](https://www.rtpi.org.uk/dementiatownplanningpracticeadvice2020.pdf) (rtpi.org.uk)

Practice Example: Planning for Dementia

Innovations in Dementia told the Inquiry about work they had done with the Royal Town Planners Institute to recognise the need for ‘cognitive ramps’ to help identify what is required for people with dementia to easily navigate town centres. The RTPI report advises that urban environments should be:

- **Familiar** – functions of places and buildings made obvious, any changes are small scale and incremental;
- **Legible** – a hierarchy of street types, which are short and fairly narrow. Clear signage;
- **Distinctive** – including a variety of landmarks and a variety of practical features, e.g. trees and street furniture;
- **Accessible** – access to amenities such as shops, GP services, post offices and banks within easy, safe, and comfortable walking distances (5-10 minutes). Obvious, easy to use entrances that conform to disabled access regulations;
- **Comfortable** – open space is well defined with public toilets, seating, shelter, and good lighting. Background and traffic noise minimised through planting and fencing. Minimal street clutter;
- **Safe** – wide, flat, and non-slip footpaths, avoid creating dark shadows or bright glare.

Case Study: Standing Up 4 Sitting Down

Anchor Hanover is running a national initiative to improve people’s access to their local high street by increasing the amount of seating available to those who need it. The ‘Standing Up 4 Sitting Down’¹² campaign was driven by older people looking for support to access and utilise high streets (Anchor Hanover, 2020). It has highlighted issues of public transport etiquette and revealed that passengers on public transport are more likely to look down at their phone or tablet than look up to see if someone might need a seat (42%) and one in five older people worry so much over lack of seating they are less likely to use public transport. Once on the high street people struggle to access their local shops and leisure facilities because of a lack of seating areas to rest in. There are now over 2000 retail outlets across the country supporting the campaign, pledging to maintain the number of seats people can use if they want to rest mid-shop.



Image Credit: Anchor Hanover

The Inquiry heard that planning for dementia should become the norm rather than the exception. The RTPI states: *“environments that are easy for people to access, understand, use and enjoy are beneficial to everyone, not just older people with dementia.”*

This is also a crucial feature to the design considerations adopted at the Building Research Establishment’s dementia-friendly demonstration home¹³.

¹² Standing Up 4 Sitting Down; Standing Up 4 Sitting Down | SU4SD | Anchor Hanover

¹³ <https://www.bregroup.com/ipark/parks/england/buildings/dementia-friendly-home/>

Case Study: Dementia-friendly demonstration home

Opened in 2018, the BRE have adapted a Victorian house to accommodate different types and stages of dementia. It is aimed at people living with dementia to live independently by addressing their day-to-day needs. The upper floor of the home has been adapted for the more advanced stages of dementia. The building design has been developed around the needs of two specific personas (or avatars), Chris and Sally. The design narrative describes how the features of the building have been adapted to support Chris and Sally as they age well at home.



Image Credit: Building Research Establishment

The Covid-19 pandemic has made stark the difficult choices faced by people about whether to stay put in their community, move to specialist housing, or move into residential care. Families and people living with dementia have made hard decisions between moving into residential care with potential isolation from family, or remaining at home with inadequate support. More information is required in the earlier stages of dementia to support positive decisions to be made about where to live rather than waiting to be pushed into a move by factors outside the control of the individual.

Realisation of the rights set out in the National Dementia Declaration¹⁴ and the Charter of Rights for People with Dementia and their Carers in Scotland¹⁵ is needed now more than ever.

¹⁴ National Dementia Declaration of Dementia Statements. National Dementia Declaration or here: Dementia Statements and rights | Alzheimer's Society

¹⁵ Charter of Rights for People with Dementia and their Carers in Scotland. ALLIANCE-DCV-Charter-of-Rights-PWDC.pdf

The dementia statement and rights reflect the things people with dementia have said are essential to their quality of life.

Practice Example: The Dementia Statements

- We have the right to be recognised as who we are, to make choices about our lives including taking risks, and to contribute to society. Our diagnosis should not define us, nor should we be ashamed of it.
- We have the right to continue with day to day and family life, without discrimination or unfair cost, to be accepted and included in our communities and not live in isolation or loneliness.
- We have the right to an early and accurate diagnosis, and to receive evidence-based, appropriate, compassionate, and properly funded care and treatment, from trained people who understand us and how dementia affects us. This must meet our needs, wherever we live.
- We have the right to be respected, and recognised as partners in care, provided with education, support, services, and training which enables us to plan and make decisions about the future.
- We have the right to know about and decide if we want to be involved in research that looks at cause, cure and care for dementia and be supported to take part.

The Dementia Statements underpin everything that older people told us during this Inquiry, and are integral to the way that evidence from professionals and organisations has been reviewed within the Inquiry. The Association of Directors of Adult Social Services (ADASS) stated that housing is central to care and to our lives¹⁶, and that people should be supported to live at home and remain in their communities unless their needs can only be met elsewhere. The rest of this report sets out what we learned and how we can make that happen.

¹⁶ <https://www.adass.org.uk/media/8036/adult-social-care-shaping-a-better-future-nine-statements-220720.pdf>

Chapter 2: Understanding dementia and planning for the best possible housing options to be available



Image Credit: Belong Ltd

Dementia is an umbrella term that is used to describe symptoms that occur when the brain is affected by different diseases, conditions, or illnesses. Dementia can cause deterioration in memory, thinking, behaviour and the ability to perform everyday activities. Symptoms can vary in the early stages of the different dementias including problems with short term memory, problems with spatial awareness or changes in language skills and decision making.

Dementia can be difficult to diagnose, especially in the early stages when symptoms may be mild¹. It was pointed out that the actual number of people diagnosed with dementia is only a proportion of the people who are living with dementia².

¹ <https://www.nhs.uk/conditions/dementia/diagnosis/>

² Diagnosis rate data available at Dementia Statistics Hub (Alzheimer's Research UK) Dementia Statistics Hub | Alzheimer's Research UK

Lack of diagnosis may also be in part because some people are not in contact with services that would provide a diagnosis or are reluctant to be assessed. The Inquiry heard from the Abbeyfield Society about specific issues related to low uptake of services from specific communities including older people from BAME communities.

Case Study: Pathways4Life The Dementia Support Worker

Accord Care and Support services for older people with dementia from BAME communities established a Dementia Support Worker role in 2012 in response to the low numbers of people accessing services from specific communities in Staffordshire and Coventry. The role aimed to increase community awareness of dementia, improve access to information and signposting, and increase the numbers of people accessing assessment and ultimately being diagnosed with dementia.

The role has been hugely successful and reaches into a variety of settings within the wider community, care settings and places of worship. The awareness sessions have been particularly effective where a healthy body, healthy mind approach has been adopted using both Accord's support workers and volunteers to ensure that sessions are available in a range of languages including Urdu, Hindi, Punjabi, and Gujarati. Through these sessions they have been able to access individuals who do not engage with traditional care services. Since the scheme was introduced hundreds of people with dementia have been supported to access appropriate assessment and diagnosis in addition to improving wider community awareness and tackling stigmas associated with dementia. A YouTube video sets out more about the Dementia Support Worker for hard to Reach Communities Service.³

³ Dementia Support Worker for Hard to Reach Communities service: https://www.youtube.com/watch?v=TF3tPw1I_fk.



Image Credit: Accord Group

Some people do not ask for an assessment either because they are unaware of the early signs of dementia or are afraid that diagnosis will lead to a loss of independence or admission into care.

Although dementia is not a natural part of ageing, we heard that the greatest risk factor for dementia is age, with 1 in 6 people over the age of 80 having dementia in England⁴. Of those people living with dementia in the UK, it is estimated that just over 40 % have mild or moderate dementia with just under 60% having severe dementia in 2020⁵.

Dementia affects families and carers as well as those people living with dementia; there are 1.8 million carers of people with dementia.

We heard from an NHS consultant in geriatrics and acute general medicine at the Royal Berkshire NHS Foundation Trust, formerly the UK Department of Health’s National Clinical Director for Older People’s Services, that many people are not diagnosed early enough.

It was unclear what constituted a diagnosis from a GP and whether a diagnosis opened a post diagnostic support programme for an individual.

One GP Practice in Greater Manchester improved the accuracy of their dementia register through a simple systematic audit of the coding, reducing the chance of the patient being lost to follow up.⁶

The NHS Consultant told the Inquiry that over 40% of people over 75 are admitted to acute hospital with dementia but only half have a previous diagnosis. He also said that it then becomes difficult to help people with dementia return from hospital to their home, and that although assessment needs to be performed outside an acute hospital setting there is shortfall in assessment and intermediate care for people with dementia in their own homes.

However, many people with dementia live well both before and after diagnosis in a range of different types of accommodation including mainstream housing, purpose-built specialist housing, and care homes as set out in Figure 1.

⁴ <https://www.dementiastatistics.org/>

⁵ Projections of older people with dementia and costs of dementia care in the United Kingdom 2019-2040. https://www.alzheimers.org.uk/sites/default/files/2019-11/cpec_report_november_2019.pdf

⁶ <https://dementiapartnerships.com/wp-content/uploads/sites/2/Barlow-Medical-Centre-Dementia-Register.pdf>

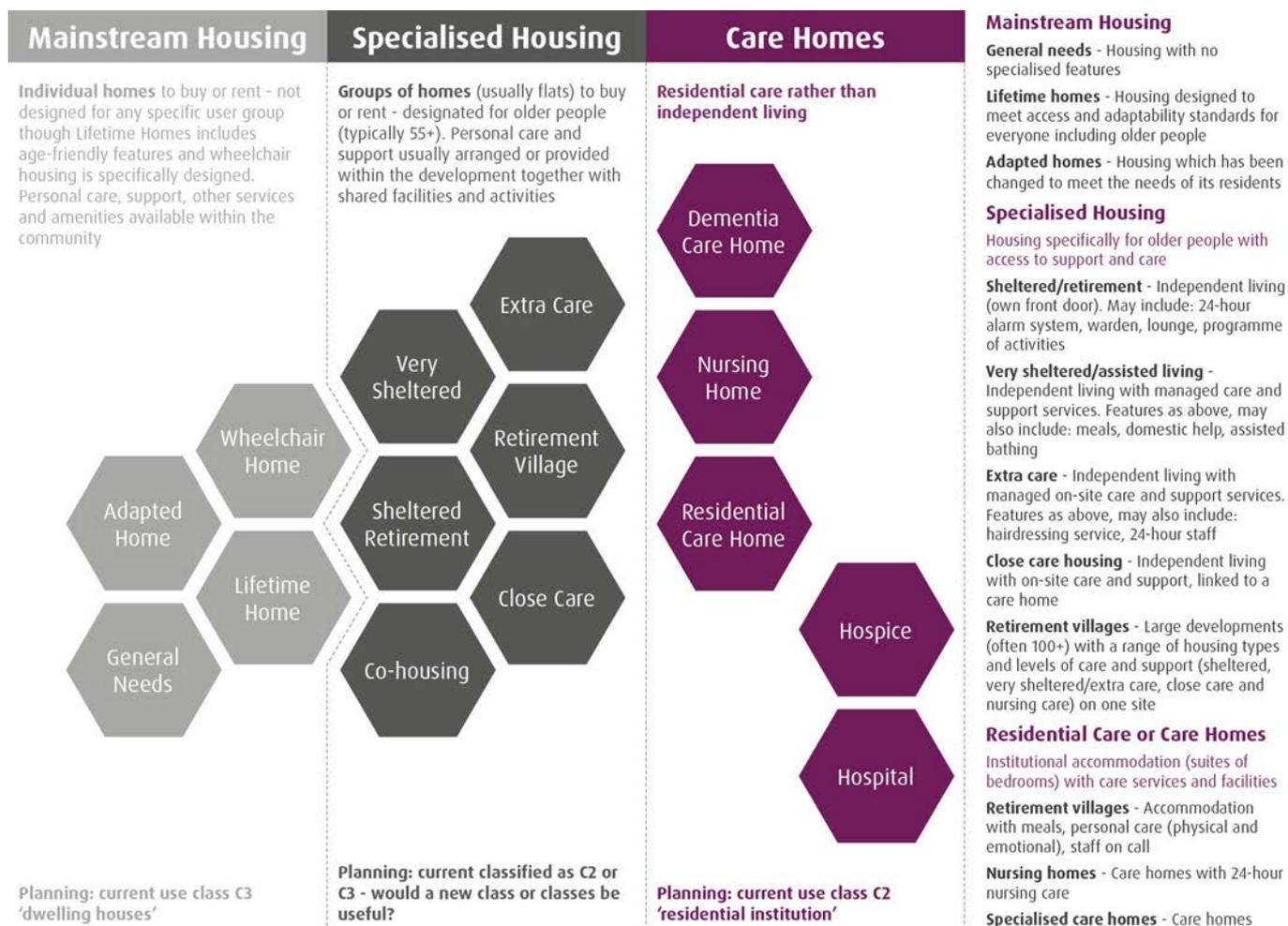


Figure 1: Different Types of Housing for Older People
Source: (Barac & Park, 2008)

The vast majority of people will live all, or nearly all, of their lives in ordinary housing, that is homes that were not built specifically for a particular age group. Given that 80% of the homes that people will be living in by 2050 are already built⁷ the condition of existing housing is critical in determining quality of life for people of all ages. Housing deprivation is significantly greater among older ethnic minority communities than for white British people⁸. For older people living with dementia housing has an even more crucial role to enable them to live independent, healthy, and fulfilling lives.

Whilst 72% of UK adults think all new homes should be built to be suitable for all ages and abilities, 48% do not think society does enough to enable people to live independently and safely at home as they grow older⁹. The balance between general housing and specialist housing for people living with dementia is a matter of current concern. The concept of dementia-ready housing could effectively start to bridge the gap between the two.

7 40% House Project. <https://www.eci.ox.ac.uk/research/energy/downloads/40house/40house.pdf>

8 Noronha N, Housing and the older ethnic minority population in England, 2019 The Race Equality and Housing LIN. HLIN_Briefing_BME_Housing.pdf (housinglin.org.uk)

9 Home and Dry: The need for decent homes in later life. Home and dry: The need for decent homes in later life | Centre for Ageing Better

What specialist housing options (types and tenures) are currently available for older people living with dementia?

UK Housebuilding, permanent dwellings started and completed by house and flat and number of bedrooms, and tenure (1991-2009) ¹

Private housebuilding (1991-2009)			Private housebuilding (2009-2019)			UK Housebuilding completed by sector (2009-2019) ²	
Housing	75%	1-bed 8% 2-bed 31%	Housing	74%	1-bed 7% 2-bed 28%	Private	79%
Flats	25%	3+ 61%	Flats	26%	3+ 65%	Housing Association	25%
All tenures housebuilding (1991-2009)			All tenures housebuilding (2009-2019)			Local Authority	8%
Housing	72%	1-bed 10% 2-bed 33%	Housing	70%	1-bed 9% 2-bed 33%		
Flats	28%	3+ 57%	Flats	30%	3+ 58%		

1 DSDC analysis of ONS-Housebuilding, permanent dwellings completed by house and flat and number of bedrooms and tenure (ENG) – ONS Table 254

2 DSDC analysis of ONS-UK House Building: Permanent dwellings started and completed, published April 2020

Figure 2: UK housebuilding by sector¹⁰

What specialist housing options (types and tenures) are currently available for older people living with dementia?

Housing trends by age and tenure (England and Wales)

75+ years ¹		60-74 years ¹		20-59 years ¹	
Owned/shared ownership	51%	Owned/shared ownership	55%	Owned/shared ownership	31%
Socially rented	35%	Socially rented	23%	Socially rented	15%
Private rented or rent free	15%	Private rented or rent free	22%	Private rented or rent free	54%

- Percentage of people aged 75 years and above within PRS has decreased from 8.1% (1993) to 5.2% (2017) but increased for people aged 55-75 years ²
- Household size for people aged 75 years and over is: 44% 1-person household and 45% 2-person household ³

1 DSDC analysis of ONS-OCT0806 - Age by tenure by bespoke accommodation type by number of bedrooms (2011 Census), published May 2018

2 ONS analysis of English housing survey data

3 DSDC analysis of ONS-CT0806 - Age by tenure by bespoke accommodation type by number of bedrooms

Figure 3: Housing trends by age and tenure (England and Wales)¹⁰

¹⁰ Information on UK housebuilding and housing trends presented as evidence to the Inquiry by the Dementia Services Development Centre at the University of Stirling.

Care and Repair England told the Inquiry that housing tenure has changed significantly in response to government fiscal and housing policies and socio-economic conditions. Today most homes are owner occupied, with the highest levels of ownership amongst older age groups. This means that for the foreseeable future, the majority of people will retire as homeowners, albeit there is a significant percentage of people living in both private rented and social rented homes. Unlike social or private rented tenants, home-owners have sole responsibility for funding and arranging any repairs, adaptations, or changes. That is likely to cause challenges for people living with dementia as their condition progresses. Social or private landlords may be reluctant to make dementia-friendly changes because of the perception that they might ‘put people off’ or that there may not be a sufficient return on their investment. The Local Government Association reported that there are issues in re-using adapted homes, especially where there have been significant state funded adaptations.

The results of the government’s recent consultation on raising accessible standards for new homes are awaited¹¹. The consultation recognised the importance of suitable homes for older and disabled people; in particular, it considered how the existing optional accessible and adaptable standard for homes and the wheelchair user standard are used, and whether government should mandate a higher standard or reconsider the way the existing optional ones are used. There is no single set of guidelines on what specialist housing for dementia should be, but there is consensus of good dementia design principles e.g. new dementia-ready HAPPI principles (See Appendix 3, pp48-49). Houses that are well designed and in line with the HAPPI design principles on the adaptability of new homes will reduce or delay demands for high cost healthcare.

The Inquiry heard recommendations for change which included the better development of Local Plans¹² and increased local strategies that focus on enabling a spectrum of ownership and rented accommodation for older people.

¹¹ Raising accessibility standards for new homes - GOV.UK

¹² The national planning policy framework (nppf) defines a local plan as: ‘The plan for the future development of the local area, drawn up by the local planning authority in consultation with the community’.

Practice Example: Derbyshire Well Pathway for Dementia

Derbyshire County Council told the Inquiry that two strategies have been developed by the Adult Social Care and Health Commissioning Team in conjunction with health, district, borough, and other key stakeholders. The Dementia Strategy¹³ has been co-produced with people living with dementia, and engagement took place with older adults in relation to the housing strategy.

Both strategies recognise that Derbyshire needs to increase the number of housing and accommodation units available to enable people to live well with dementia. This forms part of the holistic community-based person-centred approach to enabling people to live as independently as possible. Derbyshire is seeking to ensure that people are able to live in communities where there is an understanding and acceptance of dementia so that people living with dementia and their carers are respected, included and supported. One of Derbyshire’s priorities is that people can say *“I feel part of a community, and have connections to other people”*.



It was also suggested to the Inquiry that the development of new properties for older people could be stimulated by refocusing some of the requirements of Section 106 and the Community Infrastructure Levy. Greater clarity on the planning policy for specialist housing and an integrated approach across social care, NHS, housing and planning to look at whole population needs and place shaping, would help remove current barriers to provision of specialist housing for older people.

¹³ <https://www.derbyshire.gov.uk/site-elements/documents/pdf/social-health/adult-care-and-wellbeing/disability-support/dementia/derbyshire-joint-dementia-strategy.pdf>

Chapter 3: The importance of housing choice within communities



Image Credit: Belong Ltd

New homes and houses are built within existing communities. Guides currently exist on Lifetime Homes, Lifetime Neighbourhoods¹, as well as the Alzheimer’s Society’s dementia friendly guides for organisations.² The Joseph Rowntree Foundation has also published lessons learnt on becoming a dementia-friendly organisation³. These are excellent resources but we found that they are not robustly linked into planning processes or local commissioning strategies.

Current housing types differentiate between mainstream housing and specialist housing for older people. Specialist housing includes sheltered housing, assisted living, extra care housing, close care housing and retirement villages. Houses can be purchased or rented from the landlord or can be acquired with ownership shared between the individual and the landlord.

1 www.cpa.org.uk/cpa/lifetimehomes.pdf

2 Make your organisation more dementia friendly | Alzheimer’s Society

3 On the journey to becoming a dementia friendly organisation | JRF

Even where homes are purchased within specialist housing schemes there remains a private or social landlord with overall responsibility for the scheme. Specialist housing is sometimes referred to as an alternative to residential care, with an emphasis on it providing both a choice to make a preventative move (for example, in the early stages of dementia) and an alternative to residential care to save the Local Authority commissioning budget. Research has shown that there are demonstrable benefits of specialist housing (including financial) to residents and public services⁴. There is increased interest from the private sector in building specialist housing for older people.

The Inquiry heard from the Greater Manchester Housing Providers that developers should be encouraged to explore and address the needs and aspirations of older people across tenures, recognising the emerging trends in the housing movements of older people. These include older people entering or remaining in the private sector in later life, the increased number of older people experiencing divorce or separation in later life, and the increased desirability of urban neighbourhoods for the emerging cohort of older people.

The Greater Manchester Housing Providers shared the view of one resident at an award winning extra care housing scheme, Village 135, developed by Wythenshawe Community Housing Group with investment from the Department of Health’s Care and Support Specialised Housing capital grant programme. The scheme included the HAPPI design principles, and the resident talked about the appeal of the community based housing scheme which features a glazed footbridge crossing a busy road that connects two existing, remodelled residential tower blocks.

“From my point of view though it’s the convenience of everything. The shops are so close but the transport links mean we can stay connected to the community. We go to an over 60s club on Longley Lane and can get there on one bus. Or, if we want to go into Manchester or Wythenshawe, we can use the new Metrolink; we have so much choice.”

Resident of housing scheme in Wythenshawe.

4 Anchor Hanover and Sonnet – Understanding the social value of an Anchor Hanover tenancy; PSRRU etc



Image Credit: Pozzoni Architecture

Parts of the market, however, continue to build housing for older people that is not reflective of multiple occupancy requirements or the additional space needs for households that include a person living with dementia.

It is clear from the Inquiry that the planning system must play a part in helping to deliver specialist older people's housing.

The National Planning Policy Framework⁵ sets out that: *“It is important that the needs of groups with specific housing requirements are addressed when delivering a sufficient supply of homes.”* It goes on to say that: *“the size, type and tenure of housing needed for different groups in the community should be assessed and reflected in planning policies (including, but not limited to, those who require affordable housing, ... older people, ... people with disabilities, ... people who rent their homes and people wishing to commission or build their own homes).”* However, it remains silent on whether specialist housing developments should be built specifically for those living with dementia, or whether such housing should be integrated into wider communities.

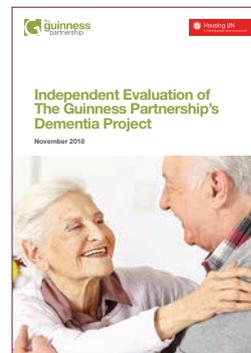
Within the specialist housing sector for older people there are a range of different models of specialist housing for people living with dementia. They include extra care housing schemes dedicated to supporting people with dementia; schemes where people with dementia live in a self-contained part or wing of the overall scheme; schemes where people with dementia are integrated and live in extra care apartments alongside other residents; and hybrid schemes where extra care apartments sit alongside other facilities such as a registered care home for people with dementia.

⁵ National Planning Policy Framework. https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/810197/NPPF_Feb_2019_revised.pdf

There is no current consensus on the best model of specialist housing for people with dementia, but members of the Housing and Dementia Research Consortium⁶ continue to look at the prevalence and benefits of each. There appears to be a move away from schemes where people with dementia are specifically housed in a separate wing. For example, Housing 21 told the Inquiry about their review of the effectiveness of extra care housing for people with dementia. In the review they compared schemes where people lived in separate wings with schemes where people were integrated throughout.

Housing 21 policy is to ensure that people with dementia are treated as individuals with the service designed around the resident's needs not their condition. We now promote generalist extra care schemes and work closely with Local Authorities to move away from separate dementia wings.

(Vanessa Pritchard-Wilkes, Housing 21)



National housing associations, including Anchor Hanover, The Guinness Partnership, and Housing 21 include specific policy statements on design to ensure that all apartments are age-friendly and supportive of people living with dementia⁷.

The Inquiry heard from Glancy Nicholls Architects about a dementia friendly housing and care village they had designed in South Derbyshire in partnership with Trident Group, Derbyshire County Council, and South Derbyshire District Council.

⁶ The Housing and Dementia Research Consortium (HDRC) is a membership group of organisations and individuals who are committed to research and knowledge exchange focusing on ‘what works’ for people living with dementia in housing and care settings. Housing and Dementia Research Consortium (HDRC) - University Of Worcester
⁷ <http://guinnesspartnership.s3-eu-west-1.amazonaws.com/wp-content/uploads/2018/11/Dementia-Report-brochure-v4B-WEB.pdf>

Case Study: Oakland Village and Community Care Centre, Swadlincote

Oakland Village is a purpose-built extra care housing scheme catering for the needs of older people and aims to help them live an independent life as well as possible. The Village is run through a partnership of housing, social services, health services and volunteers. It offers the opportunity for residents to enjoy a host of different activities, stay fit and feel young. It has a comprehensive range of facilities for people to get involved with fellow residents and the local community as much or as little as they choose. The Village has amenities that include a bar, bistro and restaurant, hair salon, and function rooms which are open to the public. There is a small shop onsite which is run mainly by volunteers who live at Oakland Village. The communal areas include access for residents and the community to computers including the internet and an assistive technology information suite for people living with dementia in their own home.

Accommodation within the Village includes 88 general extra care housing apartments for rent or purchase that have been built to be dementia friendly. There is also specialist residential care for people living with dementia and other complex needs. Within the specialist residential care there is provision for long term residents, respite care, and intermediate care, all specialising in dementia. Also included is a treatment suite providing access for residents and community medical professionals including, physiotherapist, dementia specialists and occupational therapist. A separate day care facility in the village offers support to clients from the local community across a range of specialist needs.

The Village is in an area adjacent to the town centre, used by local people. The building breaks down barriers and reduces the stigma of dementia.



Image Credit: Glancy Nicholls Architects

The Inquiry heard about the importance for people with dementia of living as part of a community, and for there to be:

“an integrated society where people with dementia live in ‘normal’ home-like situations throughout their lives with support to continue to engage in everyday community activities”

Philly Hare, Innovations in Dementia⁸

The Inquiry were told that there is a role for housing providers to reach out from their individual housing schemes to influence the development of wider dementia friendly communities. In 2013, the Alzheimer’s Society and the National Dementia Action Alliance (NDAA) set out 10 characteristics of a dementia friendly community. Similar to the RTPi recommendations for urban planning⁹, the original Alzheimer’s Society and National Dementia Action Alliance checklist below goes beyond the physical recommendations. They emphasise the need to involve older people with dementia, to challenge stigma and to have businesses and services that respond to customers with dementia.

⁸ Innovations in Dementia is Community Interest Company whose work supports people with dementia to keep control of their lives and be happy. Innovations in Dementia | Inspiring Different Conversations

⁹ Royal Town Planning Institute, Dementia and Town Planning - Creating better environments for people living with dementia, 2020. [dementiatownplanningpracticeadvice2020.pdf](#)

Practice Example: 10 characteristics of a dementia friendly community

- Shaping communities around the views of people with dementia and their carers
- Challenging stigma and building awareness
- Ensuring that activities include people with dementia
- Empowering people with dementia and recognising their contribution
- Ensuring early diagnosis, personalised and integrated care is the norm
- Befrienders helping people with dementia engage in community life
- Maintaining independence by delivering community- based solutions
- Appropriate transport
- Easy to navigate physical environments
- Businesses and services that respond to customers with dementia

Information about developing dementia friendly communities is available at the Alzheimer’s Society¹⁰.

The Inquiry were interested to learn that planning permission had recently been granted to develop a dementia-friendly ‘care’ village on the Wirral as part of a wider regeneration project.

Case Study: Wirral Waters care village at heart of vision for dementia-friendly neighbourhood

Dementia specialist, Belong, has completed the purchase of land and obtained planning consent at Wirral Waters in Birkenhead to enable building work on a £15m waterside care village which will offer specialist support and accommodation for over 100 people.

The village will provide a vital hub at the heart of the Wirral Waters urban regeneration project, with a range of inclusive spaces accessible to the local community and promoting intergenerational activity.

Designed to maximise independence and active lifestyles for people living with dementia, the development will comprise six households with 24-hour support, including nursing and dementia care, and 34 one-and two-bedroom independent living apartments, along with a range of amenities, including a waterside bistro, hair salon, gym, art studio, roof garden and balconies.



Image Credit: Pozzoni Architecture

Housing 21 described their approach to a lighter touch dementia-friendly housing which they say could meet the aspirations of people to live in ‘normal’ housing yet provide incremental access to care and support as required.

¹⁰ <https://www.alzheimers.org.uk/get-involved/dementia-friendly-communities/how-to-become-dementia-friendly-community>

Landlords offer differing levels of support. Where it works well the staff on site work as a part of a whole person-centred team to identify when a person with dementia needs a little bit more support. Further discussion is required about how a lighter touch model might vary from the more familiar models of housing, and how each can contribute to optimising the cost / benefits across the housing, health, and social care sectors. The viability of different models of specialist housing is especially important where developers are reluctant to include properties for sale in areas where market house prices are not sufficient to cover the value of the new property that has been built within the scheme.

Housing 21 also highlighted that individuality is important, and that a person's social network can help someone to consider different housing options if they know what the choices are and what things to be aware of. The difficulty in making a choice about whether to stay put or move would be reduced if all new homes are well designed and built with general characteristics to make them suitable for people with varying physical and cognitive abilities including dementia. The HAPPI design principles¹¹ and the World Alzheimer's Report 2020¹² were reviewed as part of this Inquiry¹³ and a revised set of HAPPI principles for dementia-ready housing design (set out in Appendix 3, pp48-49).

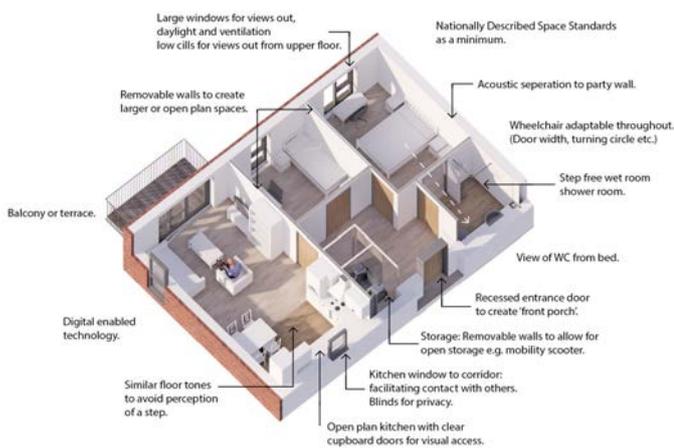


Image Credit: Pozzoni Architecture

11 HAPPI report (2008) The Housing our Ageing Population Panel for Innovation (HAPPI) Report (2008) - Resource Library - Resources - Housing LIN

12 World Alzheimer Report 2020 Design, Dignity Dementia: Dementia-related design and the built environment. World Alzheimer Report 2020 – Design Dignity Dementia: dementia-related design and the built environment, Volume 1 (alzint.org)

13 Pat Nicholls from Glancy Nicholls Architects, Damian Utton from Pozzoni Architecture and John Walker from Walker Simpson Architects

The Inquiry was told that dementia-ready principles are not currently widespread in planning, developing, or regulating new homes for people with dementia. It was pointed out that planning and delivering homes suitable for people with dementia requires knowledge of what constitutes a dementia-ready environment among architects, planning committees, constructors and building control officers.

Practice Example: Some useful design considerations

Glancy Nicholls Architects have enjoyed good relationships with a number of different authorities when designing homes for people living with dementia. However, they have found that current building regulations and their interpretation by building control officers can contradict some of the design preferences, and even prevent architects from designing appropriately for people living with dementia.

These include the following:

- Mirrors in lifts may deter someone with dementia from entering the lift. Ideally, mirrors would be removed completely, but sometimes a compromise has been reached which includes a roller blind above the mirror.
- Escape signage, particularly the “running man” signs can be confusing. These should be kept to an absolute minimum. The amount of safety signage required can cause sensory overload for someone with dementia, and compromises may need to be made.
- Glazing to internal fire doors is not always desirable, especially when leading to a private space, as it may discourage a person from opening it.
- Push plates/bars on final fire exit doors can be replaced with thumb-turns or normal ironmongery as these may remain familiar to people with dementia.
- Building Control often insist on a standard Part M pack in ambulant/disabled toilets. This design of toilet may not be appropriate, especially in specialist facilities where two carers may be required to assist someone using the toilet.

The Inquiry noted that the Dementia and Town Planning practice advice is a key document to help professionals from all those disciplines to develop shared understanding of the issues and provides a basis from which to create better environments for people living with dementia¹⁴.

Best practice in design for people with dementia continues to develop and is being shaped by what people living with dementia tells us works and doesn't work. Living well with dementia in extra care housing relies on good design and effective management of the environment, including tackling stigma and addressing prejudice among residents who don't have dementia^{15,16}. It relies on clear policy and practice to support staff, residents, and family; person centred support and care delivered through integrated teams; and residents supporting each other and being part of a community⁴⁸. Managing the complexities of place, people, and processes to support people living with dementia goes beyond the usual responsibilities of a typical landlord. Furthermore, the Covid-19 pandemic has brought fresh challenges for landlords of specialist housing for older people which have implications for design, development, and management of specialist housing in a post-Covid world.

The Inquiry heard how the St Monica Trust housing with care scheme at the heart of The Chocolate Quarter in Keynsham, on the former Cadbury Chocolate Factory, keeps residents active, socially connected and at the heart of the local community. Set in the regenerated old chocolate factory it brought the site back into use with its bar, cafes and leisure facilities acting as a hub for the town. The redevelopment includes supported housing, a residential care home, office space, swimming pool, craft room, dance studio, cinema, restaurant, and bar – all accessible to local people and designed to appeal to all ages. The Covid-19 outbreak has forced St Monica Trust to close these shared facilities to protect residents, with a subsequent impact on revenue streams. When it is safe to do so, the facilities will return to playing a key role in the life of The Chocolate Quarter fostering strong social connections among all ages.



Image Credit: St Monica Trust

The Associated Retirement Community Operators told the Inquiry that although the Covid-19 outbreak has presented great challenges to housing-with-care settings, physical distancing has not resulted in social disconnection. Housing with care settings have found creative ways to keep residents active and connected, continuing to play their important preventative role in lowering the risk of cognitive decline and dementia.

Knowledge of what can help during the Covid-19 pandemic has come from multiple sources and there is a need to share emerging and best practice in supporting people with dementia. Through collaborative presentations by groups such as the Dementia and Housing Working Group¹⁷ at key events such as the national UK Dementia Congress, learning can be shared more widely.

¹⁴ RTPI *ibid*

¹⁵ Evans SC, Atkinson T, Cameron A, et al. Can extra care housing support the changing needs of older people living with dementia? *Dementia*. 2020

¹⁶ Twyford K, People with dementia living in extra care housing: an exploration of the practicalities and possibilities, 2018. <https://etheses.whiterose.ac.uk/21390/1/People%20with%20dementia%20living%20in%20extra%20care%20housing%202020.00%20K%20Twyford.pdf>

¹⁷ Originally set up by the National Housing Federation in 2008, the Dementia and Housing Working Group aims to promote the contribution of the housing sector to improving the health and wellbeing and quality of life for people living with dementia. Dementia and Housing Working Group - Housing Networks - Housing LIN

Chapter 4: Using technology and making adaptations to improve the wellbeing of people affected by dementia



Credit Image: Belong Ltd

The majority of people living with dementia today do not live in specialist or newly built accommodation. Well thought out design can be both aesthetically pleasing and functional for people living with or without dementia, helping to make housing into a ‘home’ and helping to reduce stigma.

As highlighted in the recent House of Lords Select Committee report on ageing¹, design and adaptability (both with simple aids, adaptations and with the adoption of emerging technologies) are key to enabling independence. Poorly designed, inaccessible housing can impact on confidence and further isolate individuals in their own homes.

¹ House of Lords Select Science and Technology Select Committee, 2021. Ageing: Science, Technology and Healthy Living

An increasing number of people are living in two-person households and the creation of accessible and adaptable properties can reduce emotional and physical demands for partners/carers whilst increasing comfort and independence for those with dementia.

The Inquiry heard from the University of Stirling about work with a group of individuals, families and others who undertook evidence based assessments of their environment². Their houses were, on average, built in 1955, with many now requiring significant investment to bring them up to date and adapt them to support people living with a variety of needs, including dementia. We also heard about their new research project to better understand how best to take an inclusive living approach using technology enabled support.

Practice Example: INVITE Project (promoting INclusive liVing via Technology-Enabled support)

The INVITE project aims to investigate how assistive and everyday technologies can be implemented in retirement living properties to improve residents’ quality of life, and sustain inclusive communities. The 18 month research project is funded by the Longleigh Foundation and is being undertaken by the University of Stirling in partnership with Stonewater (a social housing provider in England) to explore how technology can support residents across three retirement living schemes to live well and safely.

The focus of the study which will report in 2022 is driven by increasing interest within health and social care policy in assistive living technologies as tools to enable older people to ‘age in place’, retaining independence within their own homes. Findings from the research will be used to develop good practice guidance for implementation of technology-enabled support that emphasises equality, inclusive design and linking people together within inclusive environments.

² The University of Stirling and Space Group developed an app called Iridis to promote a better quality of life for people with dementia which enables individuals, families, health professionals and others to undertake evidence based assessments of their environment. Iridis dementia app | About | University of Stirling

We also learned from a forthcoming report by Foundations, the national body for Home Improvement Agencies, that 3% of the national Disability Facilities Grant programme goes to people whose primary disability is dementia³. Care and Repair England also told the Inquiry that the impacts of home adaptations for people living with dementia are under researched in the UK. The most commonly installed adaptations address physical difficulties (e.g. bathing) or address safety concerns/ reduce risks (e.g. grabrails, stairlifts, door alarms).

Dementia-specific home modifications include changes to home layout (e.g. re-purpose rooms) and changing the décor (e.g. flooring) alongside the possible introduction of technology to monitor or control the environment. Technology is only of use if it meets the needs of the person with dementia and their carers, who need to see and try out some of the aids, devices, or equipment to be able to make a positive choice about their use.

Case Study: Johnnie Johnson Housing/Astraline blue-print for inclusive design

Johnnie Johnson housing described how they want inclusive design to be a blue-print for future proofing their housing schemes. At one of their schemes they have a show flat to demonstrate all the latest technology that can help residents to live independently for longer. They held a 'workshop' for residents to consider what new technology might be suitable for them and to test it out for free in their own homes. Their intention was to work with University researchers to assess the impact of the technology on the daily lives of residents and to allow the research to feedback into future developments and support for future residents. Given the current Covid-19 situation they were not able to work so closely with residents and the project was put on hold.



Image Credit: Johnnie Johnson Housing/Astraline

Understanding how aids or technology can be adapted to meet the ongoing needs of the person using them and the potential impact they can have on the wider circle of people supporting the person is essential. It was pointed out that there is limited research on the impact of home adaptations for people living with dementia. The most recent research on use of both aids and adaptations for people living with dementia⁴ reveals that small interventions may be more effective especially when used in the earlier stages of dementia when they can be responsive to changing individual need and cost effective. In addition, the Royal College of Occupational Therapists and Alzheimer's Scotland have produced tips to show what can be done in the home⁵. Although not specific for people with dementia, there are a number of on-line sites that guide people to possible equipment solutions in response to some basic questions about problems they are having with daily living, for example AskSARA⁶, MeetAdam⁷ and Living Made Easy⁸. The Dementia-friendly technology charter⁹ has been produced as part of the dementia-friendly communities strand of the Prime Minister's Challenge on Dementia, giving people with dementia and their carers information on how to access technology. It also provides guidance to health, housing and social care professionals on how to make technology work for people based on their individual needs.

³ Hussein Y, 2021. Of More Than Marginal Interest: Dementia in local housing assistance policies

⁴ Evans et al, Making homes more dementia-friendly through the use of aids and adaptations, 2019. Making Homes More Dementia-Friendly through the Use of Aids and Adaptations (nih.gov)

⁵ <https://www.rcot.co.uk/sites/default/files/Guide%20%E2%80%93%20Living%20with%20Dementia.pdf>

⁶ AskSARA <https://equipu.livingmadeeasy.org.uk/>

⁷ Adam (meetadam.co.uk)

⁸ <https://www.livingmadeeasy.org.uk/>

⁹ Dementia-friendly technology for organisations | Alzheimer's Society

In their presentation, Amica²⁴ from the Technology Enabled Care Services Association (TSA) described how use of technology to monitor activity can be helpful in recognising the point at which anticipatory care might be required as shown in the case study below.

Case study: Les in Evesham

Les was living with dementia in extra care housing. He was increasingly making journeys, including rail journeys, which potentially caused risks to his safety. His family were concerned about his safety but wanted him to retain his independence.

His situation meant he potentially might have had to leave his home in extra care housing. Alternatives were explored including specialist dementia care at great cost. Instead a GPS solution with Geo-fencing was used to keep Les independent, active, and safe. If he went missing police were able to locate him quickly and easily. With the buy-in from all stakeholders including family, carers, housing managers, and police, the tailored solution enabled Les to live an additional two years in extra care housing.

With the implementation of this TEC package, there were significant outcomes for Les and his family; his health and well-being was enhanced through his supported independence and it enabled greater personal choice in his on-going care.

TSA and Worcestershire County Council

Care and Repair England told the Inquiry that the lack of independent home adaptations and handyman services is a significant barrier to securing the adaptations that could be of most help to people with dementia. Impartial, good quality, tailored and timely information and advice is key to effective delivery of home adaptations, as is specialist assessment carried out in the early stages of dementia. Trusted Advisor and Trusted Assessor roles are important in enabling people to get the most appropriate aids and adaptations for their circumstances.

Home modifications such as these do not usually need physical adaptations to the ‘bricks and mortar’ of the home. More radical changes to property such as building extensions or knocking through rooms are possible for some people.

Barriers to home modifications or major adaptations for people with dementia include lack of knowledge of what is possible and the challenge of organising the necessary building works. It can be more complex to make adaptations or changes to achieve a dementia-friendly environment where there is a private landlord. Housing 21 described how some private landlords won't allow tenants to put notices around their house to help them navigate daily living.

Although there is a solid legislative framework for provision of help with home adaptations, including information and advice, implementation can be problematic, particularly with regard to prioritising prevention rather than crisis intervention. Housing assistance policies mentioning dementia, BAME and LGBTQ+ considerations are extremely minimal (11.5%, 8.6% and 15% respectively), confirming that the needs of individuals from these communities are not being met within the legislation²⁵. The Inquiry heard that there are system shortcomings in gaining access to adaptations, for example, through the provision of Disabled Facilities Grants (DFG's). The assessment for and provision of adaptations appear too often to fall between the cracks of different organisation's responsibilities. Housing authorities have legal duties for DFG delivery, alongside input from social services. However, the NHS is perceived as gaining most through reduced healthcare costs from the installation of adaptations.

The Inquiry were told that a review of research indicates that delays in installing adaptations can reduce their effectiveness, and that the best outcomes are achieved if individuals, families, and carers are involved in the decision making, focusing on what the person wants to achieve from the adaptation. Practical and cost effective solutions can often be achieved better by encouraging a problem-solving approach with people living with dementia. The inclusion of DFG's in social prescribing has been trialled, but Care and Repair England reported that the results have been variable. They gave local examples of innovation by home improvement agencies in delivering home adaptations; for example, through fast-tracking, proportionate means-testing and trusted assessor rapid response or targeted specific grants (see below).

Practice Example: Age UK Herefordshire and Worcestershire Dementia Dwelling Grant

This initiative, the first of its kind in the UK, enables people living with dementia to have a range of adaptations made to their home. The funding is used for changes that help the resident living with dementia to manage their surroundings; for example, from the use of colour and contrast to aid orientation, to bespoke products such as dementia clocks, to items which will help a carer to support the person.

The grant is delivered by Care & Repair Worcestershire in partnership with Age UK Herefordshire & Worcestershire and funded by the six Worcestershire district and borough councils. An evaluation¹⁰ by the University of Worcester's Association of Dementia Studies indicated positive findings which has led to the service being continued.

Although there has been some innovation in tackling wider poor housing environments with targeted funding, more is required to further improve existing housing and identify good design and cost-effective methods that will achieve dementia readiness. Further innovative examples need to be rolled out to allow people to take a long-term anticipatory approach to their housing options; either to continue to adapt and live in their current home or to explore other more appropriate options if they need to.

TSA drew attention to the 'digital switchover' by 2025 and said that technology is now also more available and is increasingly diverse and powerful, and much of it is digitally enabled. The Inquiry was drawn to a report exploring existing technologies and the opportunities for adult social care¹¹ which said:

"innovations such as smart speakers and connected household appliances really opened up the ability to keep people in their homes for longer and improve their independence."

and that...

"if existing housing could not be easily adapted to meet people's needs it was worth thinking about if the council's offer of alternative housing could be improved to encourage people to move earlier"

Rupert Lawrence, amica24 and TSA

The TSA wants to see the adoption of an early intervention, longer-term technology enabled care pathways that will contribute to the development of dementia-friendly housing. The Inquiry explored the greater complexity involved in making adaptations or changes to housing when there is a private landlord, and recognised that there is a potential issue of security of tenure for people living with dementia. It was noted that the Renters Reform Bill is aimed at providing greater stability for renters but has been delayed due to the Covid-19 pandemic¹².

¹⁰ An independent evaluation of the Dementia Dwelling Grants pilot programme

¹¹ ADASS-smart-homes-exploring-existing-technologies-report.pdf (housinglin.org.uk)

¹² Delayed at the time of writing the report in January 2021.

Chapter 5: Every decision about care is also a decision about housing



Image Credit: Anchor Hanover

The Care Act 2014¹ asserts that housing is a crucial health-related service which should be integrated with care and support and health services to promote the wellbeing of adults and carers and improve the quality of services offered. In 2020 the Association of Directors of Adult Social Services (ADASS) set out nine statements to help shape adult social care reform².

“Housing is central to care and to our lives. Every decision about care is also a decision about housing.”

James Bullion, President of ADASS

1 Care and Support Statutory Guidance: Issued under the Care Act 2014. Care and support statutory guidance - GOV.UK (www.gov.uk)
2 Adult Social Care - shaping a better future. Nine statements to help shape adult social care reform. <https://www.adass.org.uk/media/8036/adult-social-care-shaping-a-better-future-nine-statements-220720.pdf>

The ADASS report said that home and care are intertwined, and that ADASS expects to see a significant national expansion in extra care housing through dedicated funding, and that a specific housing support programme should be funded and developed to enable radical improvements to the current NHS plans for transforming care and mental health crisis support. Housing is a key determinant of equality and better care, and any changes to the whole system need to be sustained through the limited resources available.

The Housing and Dementia Research Consortium reported that, in extra care housing, 23% of residents are living with diagnosed or suspected but undiagnosed dementia³. It is believed that around a third of the 421,000 elderly people currently in residential care could be cared for more effectively in specialist housing⁴. This would require a shift in the way housing is included in social and health care assessments. It would also require staff across health, social care, and housing sectors to have sufficient knowledge to assess the housing requirements of people with dementia, and to signpost effectively.

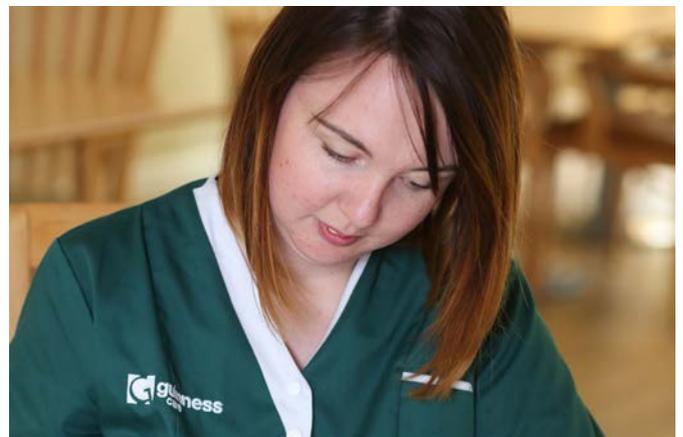


Image Credit: Guinness Partnership

The NHS workforce in England is approximately 1.3 million people and the social care workforce in England is approximately 1.5 million people⁵. Skills for Care told the Inquiry that due to the diversity of the housing workforce in England it is unclear what its size is.

3 Barrett J, Prevalence of Dementia in Extra Care Housing in the UK, 2020 https://housingdementiaresearch.files.wordpress.com/2020/10/prevalence-of-dementia-in-extra-care_june2020_final.pdf
4 <https://homesforlaterliving.org/wp-content/uploads/2019/09/Final-Healthier-and-Happier-13.09.19.pdf> quoting Enrich. Understanding Care Homes. <https://enrich.nihr.ac.uk/page/understanding-care-homes>
5 Skills for Care, The state of the adult social care sector and workforce in England, 2020 (Leeds, 2020). www.skillsforcare.org.uk/stateof.

At a local level, the three workforces of health, social care, and housing will be working regularly with people living with dementia and working with one another. However, they have separate workforce development strategies.

The Dementia Training Standards Framework⁶ provides a targeted approach to training the workforce. It is applicable but not mandatory across all health and social care settings, and does not directly target the housing workforce. There are components within the Framework that cover the central role that home, housing conditions and the immediate community play in enabling a person with dementia to live well. It emphasises how knowledge of local specialist housing accommodation and support service providers can enable appropriate referrals.

The scale and diversity of the workforce across health and social care makes implementation of Framework challenging, relying upon leaders within and across sectors to encourage adoption. The omission of housing staff from the target groups will impact on potential multi-disciplinary working across health, housing, and social care. For example, Clarion Housing told the Inquiry that they see many cases where an individual has reached crisis point before they, as landlord, are involved and assist to bring in services and help engage with families.

The Housing and Dementia Working Group, an alliance of housing operators, have produced a useful paper on skilling up the workforce⁷. The Inquiry heard about specialist roles that the different workforces have developed to support people living with dementia and to help prevent them having to move out of specialist housing or become isolated within their apartment. For example, the ExtraCare Charitable Trust (ECCT) has a specialist staff role called the ‘Dementia and Mental Wellbeing Enablers’ (originally ‘Locksmiths’) who helps with staff training, individualised case work, and liaison with health and social care teams as well as directly supporting activity and occupation and providing leadership. The original term “*locksmith*” was meant to describe staff who could help unlock the potential in those living with dementia. These staff are now called Dementia and Mental Wellbeing Enablers to better reflect the scope of the role and improve understanding amongst residents and external services.

6 Dementia Training Standards Framework | Health Education England (hee.nhs.uk)

7 https://www.housinglin.org.uk/_assets/Resources/Housing/OtherOrganisation/Making-A-Start_Full-Report.pdf

Practice Example: Enriched Opportunities Programme⁸

The Enriched Opportunities Programme (EOP) was developed by the ECCT and Professor Dawn Brooker to find ways of improving the quality of life for people living with dementia. Evaluation found that where there was an EOP programme in extra care housing, with a ‘Locksmith’ role in place, residents were:

- Half as likely to have to move out into a care home
- Far less likely to spend time in hospital as an in-patient
- More likely to have a GP visit
- More likely to see a community physiotherapist, occupational therapist and a chiropodist
- More likely to have their mental health problems diagnosed

In addition residents in the EOP schemes and villages rated their Quality of Life more positively, reported decreased symptoms of depression over time, and reported greater feelings of social support and inclusion.



Image source: ExtraCare Charitable Trust

8 Brooker D., Argyle, E., Clancy, D. & Scally A. (2011) Enriched Opportunities Programme: A cluster randomised controlled trial of a new approach to living with dementia and other mental health issues in ExtraCare housing schemes and villages. *Aging and Mental Health*. 15(8), 1008-1017

Specialist roles such as the Dementia and Mental Wellbeing Enablers, Specialist Dementia or Admiral Nurses, and social workers can help people affected by dementia to get the most effective at home care and support possible. A projection of older people with dementia and the costs of dementia care in the UK have been made by the Care Policy and Evaluation Centre⁹.

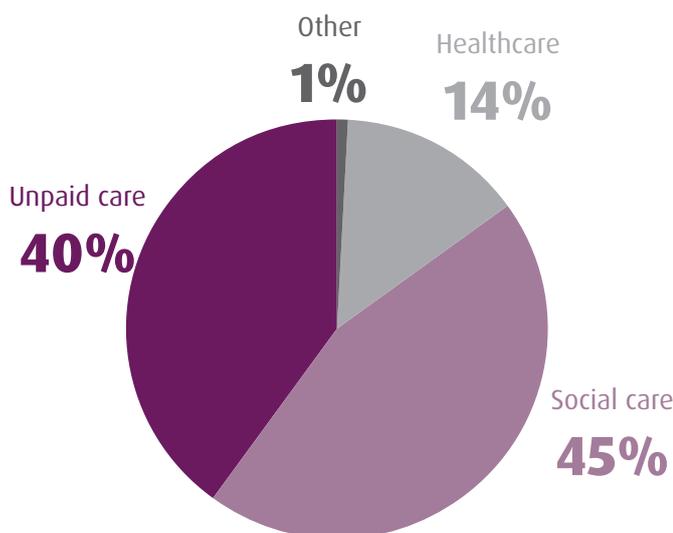


Figure 1: Breakdown of total costs of dementia care in the four UK countries 2019

It is estimated that in England in 2020 the health care costs of dementia will be £4.3 billion rising to £6.7 billion by 2030. The equivalent social care costs are estimated to be £14.5 billion in 2020 rising to £24 billion in 2030 and unpaid care costs are estimated to be £12.2 billion in 2020 rising to £19.4 billion in 2030. The projections show the large cost burden for unpaid carers providing care in the person’s home.

Carers UK told the Inquiry that carers for people with dementia find it harder than other carers, and that there were differences between carers who live with the person and those who do not. Furthermore, housing has an impact on carer’s wellbeing.

⁹ Care Policy and Evaluation Centre, Projections of older people with dementia and costs of dementia care in the United Kingdom 2019-2040, 2019. https://www.alzheimers.org.uk/sites/default/files/2019-11/cpec_report_november_2019.pdf

The critical role that people’s housing can make in helping them to live as independently as possible was set out in the Caring for our Future: reforming care and support White Paper¹⁰ in 2012. Housing can help or hinder both formal and informal carers in supporting others effectively. The impact of specialist housing on the cost of care has been evaluated since the emergence of extra care and other forms of specialist housing. The current specialist housing market is still not fully mapped and the recent King’s Fund / University of York report to scope out the evaluation of the DHSC’s Care and Support Specialised Housing (CASSH) capital grant programme suggested that further work could usefully be undertaken to understand it¹¹.

A Housing LIN report for the Local Government Association¹² estimated a shortfall of 400,000 units of housing for older people by 2030 of which 61,000 is extra care housing. The report sets out that the average person living in specialist housing for older people saves the NHS and social services between £1,700 and £4,000 per annum. The King’s Fund / University of York report found data to support savings to the NHS due to reduced elective and non-elective usage of NHS services, such as GP visits and accident and emergency attendances, and from faster transit through the health system, e.g., earlier discharge after a hospital stay. There was no expected increase in NHS costs over time as extra care housing residents age.

Living in specialist housing will result in reduced social care spending due to care package reductions, equipment, and community alarm systems and prevention of residential care costs¹³.

¹⁰ Caring for our future: reforming care and support (publishing.service.gov.uk)

¹¹ Kings Fund, Evaluating the Care and Support Specialised Housing (CASSH) programme: results of a scoping exercise, 2020. <https://www.york.ac.uk/media/healthsciences/images/research/prepare/reportsandtheircoverimages/CASSH%20report%20formatted.pdf>

¹² Local Government Association, Housing our Ageing Population; learning from councils meeting the housing need of our ageing population, 2017. https://www.local.gov.uk/sites/default/files/documents/5.17%20-%20Housing%20our%20ageing%20population_07_0.pdf

¹³ Lloyd J, Valuing retirement housing: exploring the economic effects of specialist housing for older people, 2016, Strategic Society Centre. https://www.housinglin.org.uk/_assets/Resources/Housing/OtherOrganisation/Valuing-Retirement-Housing.pdf

Anchor Hanover estimates that supported accommodation delivers additional value to the individual and local community in the region of at least £2,800 per resident, per year, made up of reduced risk of falls, reduced length of hospital stay and leaving hospital with appropriate support, reduced ambulance calls, reduced police and fire calls and fire prevention¹⁴.

The effectiveness of dementia-ready accommodation with appropriate support is increasingly being included in future plans for local authorities. For example, the Inquiry heard that Housing Services and Adult Social Care in Rotherham wish to develop their support pathways for people living with dementia. They said that more tailored packages of support could assist in keeping people in their homes for longer if support, advice, adaptations, decoration, signage, and technology are offered from an early stage. They said that by helping people maintain independence in their own home for as long as possible, care costs will reduce in the short and medium term.

There are different models of health, housing and social care provision for people affected by dementia across the country. The President of ADASS told the Inquiry that a conversation is needed with the public about needs and preferences and how to normalise locally integrated care being built around the individual. A review of how care markets operate is required and we need to address existing and historical inequalities; there may not be one single model that meets the requirements of each local population. He concluded that “*we should seek to protect our care services during any changes, but not preserve care models that many of the public do not prefer*”.



Image Credit: Glancy Nicholls Architects

¹⁴ Shah et al, Understanding the Social Value of an Anchor Hanover Tenancy: Researching and valuing the social outcomes of an Anchor Hanover supported tenancy, 2020, <https://anchorv3dev.s3.eu-west-2.amazonaws.com/documents-pdfs/Sonnet%20Social%20Impact%20Report%20June%202020%20Final%20.pdf>

Making it happen – ensuring dementia-readiness

The Inquiry heard about the housing and care experiences of older people living with dementia and their carers. It was told about the importance of planning for well-designed dementia-ready housing and how the planners, architects, developers, commissioners, and landlords all have a role to play. The Inquiry heard how people live better when their housing is integral to the local community.

There is a recognition that many people with dementia live in housing that was not purpose built to be dementia-ready. The Inquiry considered how technology, aids, and adaptations can help or hinder someone with dementia to live well. It makes recommendations to improve the wellbeing of individuals by working with them to harness technology and adapt the environment.

In conclusion, crucially the Inquiry heard that “*every decision about care is a decision about housing*” and we make recommendations to optimise the costs and benefits of an integrated approach to housing and care decisions.

Recommendations from this Inquiry can be found in the Executive Summary at the beginning of the report.

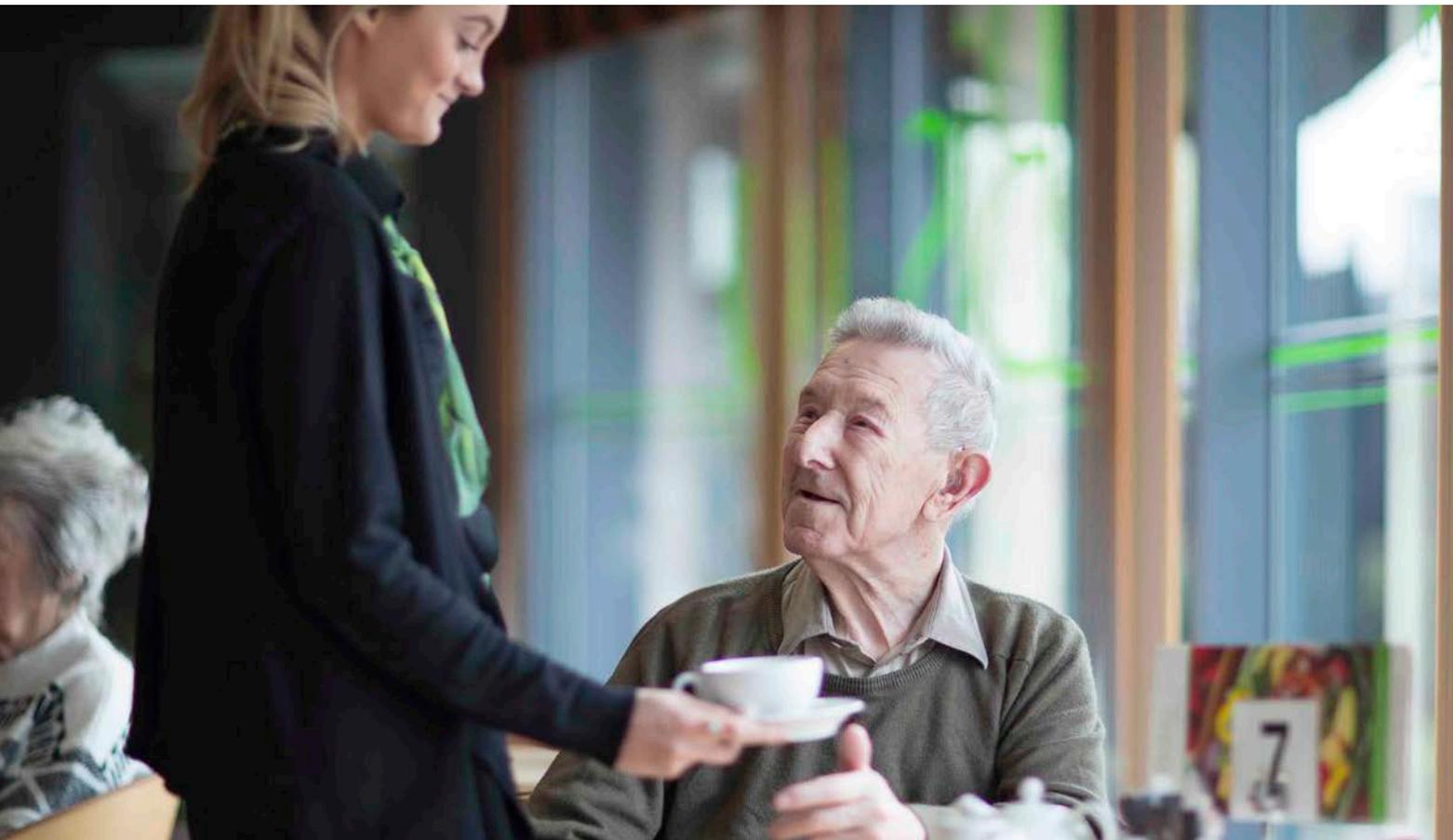


Image Credit: Belong Ltd

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Appendixes

Appendix 1: The APPG Inquiry members and witnesses

Inquiry Members: Parliamentarians who participated in the Inquiry:

- Peter Aldous MP (co-Chair)
- Baroness Kay Andrews
- Baroness Liz Barker
- Lord Richard Best (co-Chair)
- Ruth Cadbury MP
- Damian Green MP
- Lord Ben Stoneham

The APPG was also be supported by a panel of specialists:

- Jane Ashcroft CBE, Chief Executive, Anchor Hanover
- Professor Dawn Brooker, MBE, Director of the Association for Dementia Studies, University of Worcester
- Kate Lee, Chief Executive, Alzheimer's Society
- Bruce Moore, Chief Executive, Housing 21
- Sarah Pickup, Deputy Chief Executive, Local Government Association
- Damian Utton, Director, Pozzoni Architecture

The APPG heard evidence from the following witnesses:

- Wendy Mitchell, Author and person with lived experience
- Ruth Eley, The Life Story Network
- Lesley Palmer, Dementia Services Design Centre, University of Stirling
- Philly Hare, Innovations in Dementia
- James Bullion, Norfolk County Council and Association of Directors of Adult Social Services
- Professor David Oliver, Royal Berkshire NHS Foundation Trust
- Emily Holzhausen, Carers UK
- James Cross, Skills for Care
- Vanessa Pritchard-Wilkes, Housing 21
- Patrick Nicholls, Glancy Nicholls Architects
- Rupert Lawrence, amica24 and Technology Enabled Care Services Association
- Claire Days, LGBT Foundation
- Abdul Ravat, The Abbeyfield Society
- Sue Adams, Care and Repair England

Appendix 2: Individuals and organisations providing written evidence

Organisation

- Abbeyfield, Accord, BME National, Manningham Housing Association
- Care and Repair Scotland
- Northern Ireland dementia services
- Care homes
- Innovations in Dementia CIC
- Shared Lives Plus
- DLF (Shaw Trust)
- Oxfordshire County Council Adult Social Care and Oxford City Council Home Improvement Agency
- EROSH
- Joseph Rowntree Foundation
- LGA
- Jonnie Johnson Housing
- Derbyshire County Council
- Royal College of Occupational Therapists
- South Tyneside Council
- Clarion Housing Group
- Bolton at Home
- Care and Repair England
- Housing 21
- Idratek Ltd
- Association of Retirement Community Operators)
- Walker Simpson Architects
- Rotherham Metropolitan Borough Council
- Housing and Dementia Research Consortium
- Department of Health and Care Services

Appendix 3: HAPPI Design Principles and new dementia-ready design features

Over ten years ago, the very first HAPPI report, ‘Housing our Ageing Population, Panel for Innovation’ (HAPPI 1), identified ten key design elements that can characterise attractive and successful housing for an ageing population. They have now been adapted by Jeremy Porteus, Housing LIN and Secretariat to this APPG, APPG Panel Member, architect Damian Utton, oral evidence by Patrick Nicholls, Glancy Nicholls Architects, and written submission by John Walker, Walker Simpson architects, for this Inquiry to incorporate ‘dementia-ready’ features, as highlighted in italics below:

The ten HAPPI design principles (2008)	‘Dementia-ready’ HAPPI features (2021)
i) Generous internal space standards with potential for three habitable rooms and designed for flexible layouts	<i>i) Generous internal space standards that are familiar, safe, easy to understand, navigate and move around independently in order to minimise confusion, reduce risk, frustration, agitation and anger or apathy and depression. Consideration of acoustic performance including internal, neighbour and outdoor environment.</i>
ii) Plenty of natural light in the home and circulation spaces	<i>ii) Plenty of natural light with good visual access, varied views and vistas to create a connection with the outside world and aid orientation. High levels of good quality shadow free daylight, but avoiding glare, and artificial light at night Ideally, east/west orientation for habitable rooms to ensure direct sunlight during the day</i>
iii) Balconies and outdoor space, avoiding internal corridors and single-aspect flats	<i>iii) Balconies and ease of access to outdoor space, avoiding long internal dead-end corridors and single-aspect flats that might isolate someone with dementia. Consider benefit of balcony winter gardens and covered terraces.</i>
iv) Adaptability and ‘care aware’ design which is ready for emerging telecare and telehealthcare technologies	<i>iv) Future adaptability and modifications which are ‘dementia-ready’ and can also incorporate devices and equipment, including digitally enabled technology or smart sensors. Home/ site broadband connectivity.</i>
v) Circulation spaces that encourage interaction and avoid an ‘institutional feel’	<i>v) Generous circulation spaces that are recognisable, clear, step free and easy to navigate without reliance on signage, lead to an activity/destination to encourage social interaction. Domestic scale to avoid an ‘institutional feel’ or over stimulation. Provision of seating alcoves, effective colourways and points of interest (e.g. art/pictures) to aid wayfinding.</i>

The ten HAPPI design principles (2008)	'Dementia-ready' HAPPI features (2021)
vi) Shared facilities and community 'hubs' where these are lacking in the neighbourhood	<i>vi) Open and welcoming access to outward facing, on-site shared facilities or community 'hubs' within easy reach so as to support and provide opportunities for engagement with other people and/or services in a multi-generational environment. Flexible spaces to provide opportunities for both social interaction and quieter, intimate scale spaces</i>
vii) Plants, trees, and the natural environment	<i>vii) Providing helpful stimulation and clear orientation with easy access to green space, natural landscape with visual enhancing and fragrant planting that engages the senses, encourages bio-diversity and areas for points of interest exercise or resting and sitting places. Consider outdoor surfaces, covered spaces, textures and contrasts, looped paths and opportunities for purposeful activity e.g. raised planting beds for gardening clubs</i>
viii) High levels of energy efficiency, with good ventilation to avoid overheating	<i>viii) Energy efficient low carbon design and specification - affordable and comfortable, with the building orientation, use of shading and good ventilation to avoid overheating. Easy to use/ understandable and familiar looking controls</i>
ix) Extra storage for belongings and bicycles	<i>ix) Extra storage for personal belongings within individual dwellings and ease of access to mobility and other aids</i>
x) Shared external areas such as 'home zones' that give priority to pedestrians	<i>x) Hazard free external environment, well-lit and appropriate use of signage/cues and level pedestrian access with close proximity to accessible public transport and neighbourhood amenities</i>

More information on HAPPI, including case studies on new purpose-built homes for older people that have been influenced by the HAPPI design principles, can be found at: www.housinglin.org.uk/HAPPI/.

Appendix 4: Useful weblinks

Charities and voluntary organisations	National housing organisations
<ul style="list-style-type: none"> • Alzheimer’s Society • Dementia Friends (An Alzheimer’s Society initiative) • Dementia UK • Innovations in Dementia CIC • Life Story Network • Tide UK (Together in Dementia Everyday) • Dementia Voices • Dementia Connect 	<ul style="list-style-type: none"> • In Focus: Innovations in Housing and Dementia (Housing LIN) • The Dementia and Housing Working Group
Government and national health and care bodies	Academic organisations
<ul style="list-style-type: none"> • Department of Health Dementia Strategy • NHS England - dementia • Public Health England – dementia profile • All Party Parliamentary Group on Dementia • SCIE – Dementia Gateway 	<ul style="list-style-type: none"> • The Housing and Dementia Research Consortium • Stirling University – Dementia Services Development Centre • Nesta - Dementia Citizens

Image Credit: Anchor Hanover





Housing LIN

Connecting people, ideas and resources

Copies of this report can be downloaded from the dedicated APPG Inquiry webpage on the Housing (LIN) Learning and Improvement Network's housing and dementia webpages at: <https://www.housinglin.org.uk/APPG-Housing-and-Dementia>

The Housing LIN is a sophisticated network that brings together policy makers and practitioners to champion better quality housing and health and care services for an ageing population. To access a range of other resources on housing and dementia curated by the Housing LIN, visit: <https://www.housinglin.org.uk/HousingandDementia/>

And to access copies of this APPG's previous HAPPI Inquiry reports, visit: www.housinglin.org.uk/HAPPI/

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This APPG Inquiry is supported by Anchor Hanover

Anchor Hanover is England's largest not-for-profit provider of care and housing for people in later life, with more than 60,000 customers in 54,000 homes across almost 1,700 locations, supported by more than 10,000 colleagues. Anchor Hanover provides retirement housing to rent and to buy, retirement villages and residential care homes, including specialist dementia care, operating in more than 85% of local councils in England. For more information visit www.anchorhanover.org.uk.

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