Housing and Living Well with Dementia

from Policy to Practice in Greater Manchester
Acknowledgments

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Housing and Living Well with Dementia

This work is specifically focused on housing in community settings in Greater Manchester. It has been undertaken through collaboration between the Greater Manchester Health and Social Care Partnership Strategic Leads (Dementia United, Housing and Health), and the University of Manchester’s Healthy Ageing Research Group (HARG) and the Manchester Institute for Collaborative Research on Ageing (MICRA).

There is growing recognition that dementia is not an inevitable feature of ageing and that, when it does occur – whether in younger or older people – early diagnosis and appropriate intervention can moderate both the impact and the progress of the disease.

One such moderator is the home in which we live, and which fundamentally structures our capacity to age well. Yet there is well documented evidence that current housing stock in the United Kingdom does not meet the needs of ageing populations and/or those living with dementia. Such needs are shaped by a diverse range of socio-demographic factors and how these play out across the life-course, including age cohort, gender, education, ethnicity, sexual orientation, family and social circumstances, financial assets and resources, and health status.

Introduction

This report presents evidence and recommendations on potential interventions in housing to improve the lives of people living with dementia.

Dementia is the most common form of cognitive impairment in older people and its prevalence globally is growing. It has been defined as: “a syndrome of widespread, progressive and irreversible loss of brain functions occurring in clear consciousness... manifested by deterioration in memory, disorientation, decline in intellectual functions such as language and capacity to learn, as well as changes in personality, emotions and behaviour.” (p.5, 2) The disease can range from mild to moderate to severe, and has a number of causes including Alzheimer’s Disease, Vascular Dementia, Dementia with Lewy Bodies and Frontotemporal Dementia amongst others (9). These share the same main symptom of a deterioration of a person’s capacity to think or remember (9). Dementia is recognised as one of the most serious challenges we face globally, nationally and locally, with individual and societal impacts outstripping cancer and cardiovascular disease. (10-12) In 2015, dementia affected 47 million people worldwide (5% of the world’s older population), a figure predicted to increase to 75 million in 2030 and 132 million by 2050. (9) In the UK, the number of people living with dementia is predicted to rise to one million by 2025. (13-15)
There are 209,600 new cases of dementia in the UK each year.

According to the Social Care Institute for Excellence: (14)

- There are over 25,000 people with dementia from black and minority ethnic groups in England and Wales, and notwithstanding the limitations of existing surveys, this is estimated to rise to 50,000 by 2026.
- There are 209,600 new cases of dementia in the UK each year.
- Two-thirds of people with dementia are women; over 600,000 women in the UK are now living with dementia. The condition is the leading cause of death in women in the UK.
- For lesbian, gay, bisexual, transgender + people (LGBTQ+), evidence suggests living with dementia can be even more challenging than for heterosexual people.

Almost all those living with dementia (91.8%) also have another long-term health condition: 33.8% have two or three, 27.8% four or five, and 16.9% have six or more. (9, 16-18) Social participation and inclusion is recognised as central to living well with dementia. (19) However, in a recent study, one-third of people with mild-to-moderate dementia in the UK experience loneliness; 30% were moderately lonely and 5% severely lonely, with those who live alone, and who experience social isolation, depression and lower quality of life, more likely to feel lonely. (20) The costs of care for people with dementia for the UK as a whole is in excess of £34.7billion and a recent report for the Alzheimer’s Society (21) notes that:

- This is set to rise sharply over the next two decades, to £94.1billion in 2040.
- These costs are made up of healthcare costs (costs to the NHS), social care costs (costs of homecare and residential care), and costs of unpaid care (provided by friends, family members and loved ones).
- The largest proportion of this cost (45%) is social care, at £15.7billion.
- Social Care costs are set to nearly triple over the next two decades, to £45.4billion by 2040.

One-third of people with mild-to-moderate dementia in the UK experience loneliness.
Dementia in Greater Manchester

The North West region has the second highest number of deaths in England and Wales due to dementia and Alzheimer’s Disease, and the second highest population rates. (12)

In 2019, at least 21,851 Greater Manchester residents were living with dementia, including 1 in 25 diagnosed with Younger Onset Dementia. (24)

Greater Manchester, like many areas of the UK, has older populations. However, this varies across the city-region’s 2.8 million residents and its ten Local Authorities. Overall it has a younger population than the surrounding region and when compared nationally, weighted heavily by a younger population in the metropolitan core around the city centre. (24) As the Greater Manchester Strategic Housing Assessment (2019) notes, within many outer districts of Greater Manchester populations are ageing. (24)

The districts of Wigan and Tameside are expected to experience the largest increase in the numbers of people with dementia at over 70%.

There will be a 43% rise in people aged over 65 living alone.

Almost 8% of over 65s are predicted to have dementia in 2035, an increase of 63.3%.

Almost 1 in 3 people aged 65 or over will have a long-term illness that limits day to day activities ‘a lot’.

There is a projected increase for all age groups over 55, with the oldest age group of over 85 expected to increase by 79% between 2016 and 2036.

Greater Manchester

By 2035, 3 in 20 residents in Greater Manchester will be 75 years or older, and 1 in 20 will be 85 or older. This represents an increase from 1.9% of the total population in 2016 to 3.2% in 2036. By 2036 this is expected to rise to 5.6% for those aged over 85, and 11.5% for those aged 75 to 84.

There are higher concentrations of older people most notably in districts to the south (Stockport and Trafford), to the east of Oldham and the border of Bolton and Bury.

However, all this data should be treated with caution given the concern about the global and persistent underdiagnosis of dementia, with estimates ranging from one third to 95%, with as much as 60% in high income countries (1, 26) and worsened by the Covid-19 pandemic which has led to a sharp fall in diagnosis in the UK. (27)

There will be a 70% rise in people requiring accommodation with high level support.
Housing and Living well with Dementia

This report is in keeping with current national priorities to raise standards for new homes in England and improve the existing housing offer.

Embedded within housing priorities is the importance of identifying and addressing the needs of diverse populations. In response to the changing demography and rising number of people ageing with dementia such priorities have been translated into a raft of policies - locally, nationally and globally. These policies are a reflection of the increasing emphasis put upon housing and an acknowledgement of its central relationship to improving quality of life. Including through promoting healthier lifestyles, tackling mental health problems and the more effective and efficient delivery of preventative health and social care services for all, not least for those living with dementia and their carers.

To deliver such improvements and foster independence and choice, the new housing offer needs to be person-centred, supportive, accessible and built around local communities.

This demand to re-envision and re-shape the housing offer has been intensified by Covid-19. The pandemic has highlighted the profound impact on mental health across the whole of society, not least because of the enforcement of physical lock-down. Yet such lock-down is an arguably taken for granted aspect of life for many living with dementia, and for their informal carers.

The impacts of the pandemic have not been equally felt however, and it has heightened challenges posed by existing deep inequalities, structural racism and ageism, and stigma documented across the housing, health and social care sectors. (30, 31) Such challenges are further exacerbated by a preponderance of older properties that are not fit for purpose, rising vacancies in existing stock, and a context of increasing national austerity. (32)

Understanding the housing needs of those living with dementia offers a valuable opportunity to develop exemplars that future-proof housing for all. Such an approach reflects principles of solidarity, mutuality and reciprocal help, and can help address issues of isolation, loneliness, lack of support and autonomy faced by a wide range of people, across all ages and communities.

Against this background, this report has three objectives:

First, we present a review of the literature and policy developments.

Second, we provide a strategic system wide analysis developed through a series of consultations with key stakeholders. The analysis includes mapping of provision across Greater Manchester; a gap analysis covering medium and long-term need.

Third, we outline a series of recommendations, including potential implementation mechanisms based on the findings.

Finally we identify a range of next steps, in particular focused on implementation and evaluation.

In compiling this report we are seeking to reflect what 'good/excellent' would look like, whilst acknowledging the extent of our influence, and the need for collaboration from many other sectors in order to develop a commissioning framework that can deliver housing to enable individuals and our communities to live well with dementia.
The first part of this report consists of a rapid evidence assessment of the academic and grey literatures, e.g., policies, research reports from non-governmental organisations in addition to peer-reviewed research reports (see Appendix 1 for literature review methodology).

As with ageing, living with dementia is unequal because of many intersecting dimensions of inequality “which operate simultaneously and often in combination.” Consequently, we begin by examining the broader socio-political dynamics of living with dementia as the context within which the capacity and opportunities to address housing needs is embedded and needs to be understood. We then examine the relationship between housing and the capacity to live well with dementia.
1.1 The social context of dementia

In contrast to the medical model, which defines disability primarily in terms of bio-medical facts about the individual, the social model sees people with a physical or cognitive impairment as also disabled by the barriers created by the social environment in which they live.

Consequently, in addition to traditional medical support, care practices and policies based on the social model would aim to modify the external environment to remove socially constructed barriers and enable people with impairments to function well... a social model of dementia provides a good foundation for planning and evaluating dementia care policy and practice.

There is increasing understanding of the social dimensions to living well with dementia – both at the level of personal relationships and social inclusion, and interaction with natural environments and public spaces – and how these are central to creating and maintaining a nurturing and supportive home environment.

Three dimensions have been highlighted as key: Social Flourishing (close personal relationships and social support); Contentedness (emotional well-being); and Safety-Security.

Calvert and colleagues highlight three major policy and service developments driving this focus on social well-being:

1. **Empowerment**: the global reframing of dementia as a public health priority, with the recognition that people living with dementia are themselves agents of social change.

2. **Human rights**: the enshrinement of human rights for people living with dementia under the World Health Organization’s Global Plan for Dementia and its emphasis on empowering and person-centred language and narratives such as ‘living well with dementia’.

3. **Citizenship**: the dementia-friendly community movement to enhance social and relational citizenship.

Within the context of these three drivers, we suggest there are a number of issues to take into consideration which include (but are not limited to): discrimination; diversity in terms of lived experience; and informal support networks.

1.2 Discrimination

To fully appreciate and address the complexity of living with dementia, and the implications for policy and practice, at least five contextual issues related to discrimination should be considered, all of which are inter-linked: structural ageism, language and terminology, inequalities, ethnicity and culture, and the impact of the Covid-19 pandemic.

1.2.1 Ageism

Whilst dementia is not limited to older people, it is perceived as an older person’s condition (2, 3, 43) and so the first issue is structural ageism.

Regardless of our own age, it is estimated that one in two of us hold ageist views. (47) Although the drivers of these are beyond the scope of this report, it is important to note its profoundly negative impacts on health, social isolation, mortality and economic costs. (47)

Old-age exclusion involves interchanges between multi-level risk factors, processes and outcomes. Varying in form and degree across the older adult life course, its complexity, impact and prevalence are amplified by old-age vulnerabilities, accumulated disadvantage for some groups, and constrained opportunities to ameliorate exclusion. Old-age exclusion leads to inequities in: choice and control, resources and relationships, and power and rights in key domains of neighbourhood and community; services, amenities and mobility; material and financial resources; social relations; socio-cultural aspects of society; and civic participation. Old-age exclusion implicates states, societies, communities and individuals. (p.93, 48)
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People living with dementia and their family caregivers perceived negative stereotyping, prejudice and discrimination from both the public and health care professionals.

As with other forms of discrimination, ageism normalises inequities, and vulnerability becomes biological and acceptable. There is a growing evidence base of the negative impact of discrimination on health outcomes. Moreover, in their systematic review of the global literature, Nguyen and Li (2020) found that people living with dementia and their family caregivers perceived negative stereotyping, prejudice and discrimination from both the public and health care professionals. Such reactions resulted in negative self-esteem and worth, and delays in help-seeking. Such discrimination is rooted in stigma, which itself acts as a significant barrier to health seeking behaviour and care globally, because, not least, of worries on the part of the individual of the responses they will receive from others for something that is outside of their control.

1.2.2 Language and terminology

Linked to the issue of ageism is that of language which shapes and reflects values, beliefs and attitudes, both at an individual and a societal level. Not least, it has enormous influence in maintaining, or challenging, prejudicial discourses that can result in stereotypes, prejudices and discrimination.

The enshrinement of human rights for people living with dementia under the World Health Organization’s (2017) Global Plan for Dementia, is a change underpinned by the use of empowering and person-centred language. It recognises that, in separating ‘us’ from ‘them’, or ‘agency’ from ‘vulnerability’, we remove the power that vulnerable populations have to act upon the social contexts driving their experiences, behaviours, and actions, and undermine the dignity and value of such individuals. Such dichotomies also lead to a simplistic view of vulnerable populations as a group of individuals defined and connected only by the ‘attribute’ of their vulnerability.

They identify a number of consequences to such homogenisation in the context of the pandemic (see below), but which we argue apply more generally and have particular pertinence to this report:

1. It alienates people.
2. It fosters inter-generational conflict.
3. It causes confusion in public health messaging because it is not specific.
4. It masks racial and sexual disparities in access to health care.

It plays into age- and disability-based triage policies in health and social care practice.
1.2.3 Inequalities

Although one of the world’s most advanced economies, [59] recent analysis indicates that the UK has had its weakest growth in life expectancy for over a century, with a significant decline for the poorest 10% of women. [61] The health gap has grown between wealthy and deprived areas over the past ten years, and ‘place matters’: living in a deprived area in the North is worse for our health, with a lower life expectancy of 5 years compared to living in a similarly deprived area in London. [61]

The proportions of older people in poverty have altered relatively little since the mid-1990s, with some groups disproportionately affected. Indeed, the groups who have historically been most acutely affected by poverty are still those most likely to live in low-income households. This includes (single) female pensioners, people aged 75 and over, those belonging to some black and other ethnic minority groups, and older people living in deprived communities. [63, 64] Such poverty is directly correlated to poor health. [61, 65-67]

1.2.4 Ethnicity and culture

There is increasing recognition of the impact of ethnicity and culture on health, and a growing realisation of the importance of focusing behaviour change and public health interventions beyond the level of the individual to that of the family, community and larger society. [70-72]

The terms ethnicity and culture hold a multitude of difference meanings [73] and so it is important to be clear what each encompasses. Furthermore, it is worth noting that whilst racism is real, the term race is avoided as it ‘essentializes and stereotypes people, their social statuses, their social behaviours, and their social ranking’. [74]

Ethnicity refers to one’s affiliation to a culturally distinct community in which members may share the same language, religion, sense of history, traditions, and values. [2] However, recent research has also pointed to the importance of the open and fluctuating nature of ethnicity, and the need to take into consideration ordinary people’s understanding of the term. [73] Culture is considered to be a shared set of values, norms, codes that collectively shape individual and group beliefs, attitudes and behaviours – not least in relation to health - through their interaction in and with their environments. [72-74]

The intersectionality of race, ethnicity and dementia will be explored further below.
1.2.5 The Covid-19 pandemic

At the time of writing, the Covid-19 pandemic is beginning to emerge from its third wave in the UK, with the country having one of the highest death tolls as measured relative to population size in Europe. (7) To contain the spread, the government implemented a range of measures, including travel restrictions and social distancing measures. However, in its 2020 report the Equality and Human Rights Commission highlighted serious concerns about the breach of human rights of disabled people, age discrimination, and deepening inequalities resulting from the pandemic. It called for incorporation of the right to independent living into domestic law so as to protect the human rights of disabled people during and following the pandemic. (77)

Apart from increased mortality, the impacts of the virus on those living with dementia, and the measures taken to contain it, have been significant. These include increased memory loss, difficulty concentrating, agitation/restless and stress or depression, not least because of the need to isolate from their regular support systems, cope with the fear generated by the pandemic and the widespread belief in misinformation.

Such impacts are further exacerbated by socio-demographic factors and emphasise yet more the importance of the home and with it the need for expanded access to essential services including mental health and home care aides. (78-84)

In addition, as we shall explore in the report, the pandemic has intensified the challenges already evident across provision in the housing, health and social care sectors, including rising vacancies and precarious financial viability, and highlighted the need to reshape the market by providing a new housing offer that is person-centred, supportive and built around local communities; one that is aimed at improving quality of life and fostering independence, dignity and choice for both those living with dementia and for their carers. (5, 83)
1.3 Diversity

Despite an increasing recognition of the diversity within older populations, homogenisation remains problematic on myriad levels, including the persistent othering of older people and perpetuation of negative stereotypes. (85, 86)

Diversity amongst older populations – as in any other cohorts - is shaped by the intersection of features such as gender, sexuality, disability, etc., with a variety of life-course factors such as roles, life stages, transitions, age/cohort, cumulative disadvantage/advantage, and trajectories. (34, 87)

We take two exemplars to indicate the importance of considering such diversity in the context of life-course intersectionality when developing policies and practices: ethnicity and sexual orientation.

Exemplar 1: Ethnicity

The UK’s population of 56.1 million is officially made up of 18 ethnicities: (88)

- White (English, Welsh, Scottish, Northern Irish or British Irish, Gypsy or Irish Traveller, any other White background)
- Mixed or Multiple ethnic groups (White and Black Caribbean; White and Black African; White and Asian; any other Mixed or Multiple ethnic background)
- Asian or Asian British (Indian, Pakistani, Bangladeshi, Chinese, any other Asian background)
- Black, African, Caribbean or Black British (African, Caribbean, Any other Black, African or Caribbean background)
- Other ethnic group (Arab; any other ethnic group)

Disadvantage is evident in the ways that Covid-19 has disproportionately affected ethnic minority groups in developed countries including the UK, with those of black ethnicity having the highest diagnosis rates, a key determinant of which is overcrowded housing. (51, 89-92) Although there is variation across groups, most minority ethnic populations live in the private rented sector, associated with poorer housing conditions and higher rents compared to the social rented sector, with high rates of multi-generational households and overcrowding a serious issue. (93) Such environments make it harder to practice safe social distancing and shield those most at risk of adverse outcomes from the virus, vulnerability exacerbated by the higher incidence of co-morbidities in these groups (93) and the lack of translated and effectively disseminated advice related to COVID-19 and NHS accessibility. (94)

In terms of health-related quality of life in England generally, inequalities are deepest for Gypsy or Irish Traveller, Bangladeshi, Pakistani and Arab, and more so for women. Such inequalities are associated with increased prevalence of long-term conditions or multiple long-term conditions, poor experience of primary care, inadequate support from local services, low confidence in self-management, and high area-level social deprivation compared to those who are White British. (97) In addition, UK Government statistics for the financial years ending 1995 to 2020 show that poverty rates are highest for people in households where the head of the household is from Pakistani or Bangladeshi ethnic groups, and lowest for those from White ethnic groups. (98)

Religious and cultural values and beliefs play a key role in health disparities, and in expectations of care and services. (99, 101) Banerjee and Lawrence (2) note that religion is often considered one of the most important aspects of the traditional Caribbean community, principally Catholicism and Protestantism. In terms of South Asian communities, over 80% practice Hinduism and 12% Islam, with Sikhism also having a prominent role. For many members of both diasporas, their religions are a way of life. In common with other faith communities, such as Judaism, this can lead to specific cultural requirements in relation to care and support, again including the development and availability of relevant, culturally sensitive, and focused advice and information. (2, 73, 101-103)

More specifically in terms of dementia, minority ethnic groups living with the condition and their carers face difficulty in accessing services and often access services later, in part as a result of stereotyping by service providers who often see minority ethnic communities in terms of ‘they look after their own’, with services and information often not culturally appropriate. (101) Choice in care and support services is also limited because of lower levels of awareness about the condition and higher levels of stigma. (101) Moreover, people from differing ethnic backgrounds may interpret symptoms of dementia in different ways – a part of ageing: a sign of madness - and apply different causalities – social isolation, God’s will - all of which will shape responses to the condition. (99)

Exemplar 2: Sexual Orientation

Despite increasing recognition of the diversity within older sexual orientations, homogenisation remains problematic on myriad levels, including the persistent othering of older people and perpetuation of negative stereotypes. (99)

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Exemplar 2: Sexual Orientation

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Exemplar 2: Lesbian, Gay, Bisexual and Trans+ communities

In a rapid review, the Centre for Policy on Ageing (2021) note that although lesbian, gay, bisexual and trans individuals, both throughout life and in older age, are often grouped together yet they form a diverse and heterogeneous group. While the terms ‘lesbian’ and ‘gay man’ may suggest a clear sexual orientation in reality, sexuality can be much more fluid in individual lives. Trans, which does not indicate sexual orientation, is an umbrella term which is increasingly employed to cover the gender identity spectrum including (but not limited to) transgender, transfeminine, genderqueer, gender-liquid, non-binary, genderless, agender, nongendered, third gender, two-spirit and bigender.

Although set to improve with the recent 2021 census, little data currently exists on the demographic composition of the LGBTQ+ population in the UK as no question on sexual orientation was included in the previous (2011) census. The evidence base in the UK comes primarily from population level surveys commissioned by Stonewall and local authorities because sexual orientation has only been included in surveys by the Office of National Statistics since 2011. There is ongoing work to improve data collection on sexual orientation, particularly in NHS data, and a developing narrative about how to collect gender identity data at a population level. (105, 106) It has been argued that the experiences of older LGBT individuals in the UK have been structured by growing up in a period when homosexuality was illegal, or only recently legalised and, along with transgender, was classified as a form of ‘mental illness’. (107, 108) Evidence suggests that members of these communities experience health inequalities across a range of conditions and diseases that result in lower life expectancy and increased morbidity.

Some of this is a reflection of the disproportionate distribution of infectious diseases such as HIV and hepatitis, some reflects increased health risk behaviours such as smoking, alcohol and drug misuse, and some is a result of worse mental health correlated with experiences of discrimination and marginalisation from family, friends and wider society. (106, 108, 109) However, even taking into account the variable sources, combined with the international research evidence base, the inequalities are stark, resulting in cumulative, multiple disadvantage in later life:

- Lesbian and gay youth are more likely to smoke and exhibit risky drinking behaviour than their heterosexual counterparts, and bisexual youth are more likely to smoke.
- One in 20 gay and bisexual men in the UK are living with HIV; this rises to 1 in 11 in London.
- In a large US population survey, 46% of bisexual-identified female respondents reported experiencing rape (at some point in their life), compared with 17% of heterosexual women and 13% of lesbian women.
- Over half of lesbian, gay, bisexual, trans and questioning (LGBTQ+) respondents (52%) in the Youth Chances survey reported self-harming, either now or in the past. This compares to 35% of heterosexual non-trans young people and to a rate of 12% for this age-group that self-reported in a household survey by the NHS in 2007.
- 88% of trans people reported that they have experienced a mental health issue, over 37% have experienced physical threats or intimidation for being trans and 19% have been hit or beaten for being trans.
- Older LGBTQ+ people are two and a half times as likely to live alone, twice as likely to be single and four and a half times as likely to have no children to call on in times of need as their heterosexual counterparts.
- Those who come from another minority identity, e.g. living with a disability or an ethnic minority group, experience compounding impacts of discrimination and marginalisation.

For decades, Lesbian, Gay, Bisexual and Trans+(LGBTQ+) communities in the UK have looked enviously at other countries, such as Australia, Germany, Sweden and the USA, where LGBTQ-specific housing projects existed for older people. The generations who fought for our LGBT rights in decades past may find themselves isolated and fearful of the future, dreaming of a housing scheme where they could live out the rest of their lives with others from their family of choice, where they did not have to hide their identity.

Bob Green OBE (104)
Nearly 50% of LGBTQ+ people living in social housing do not feel a sense of belonging in their local community and over 25% report feeling lonely in the area they live.

Moreover, whilst many of the concerns of the older LGBTQ+ population are the same as for all other older people, i.e. adequate income, good health, and social connection and inclusion, As they age, members of these communities often fear interaction with healthcare services because of worries about mistreatment and discrimination. Such fears can lead to late presentation, treatment compliance issues, identity concealment and mental distress, including suicide ideation, all leading to worse clinical outcomes. There is increasing recognition of the need to address the gap in training of health care professionals on the health needs of LGBT people or how to support them better in health and social care settings. In addition, there is growing evidence of the isolation experienced by many LGBTQ+ people as they age, and of the importance of promoting LGBTQ+ community connectedness not least in reducing the risk for suicidal behaviour.

It is no surprise then that the onset of dementia can heighten and multiply the challenges resulting from the intersectionality of sexuality, stigma and illness outlined above. A common dementia-related concern for an older member of the LGBT community, for example, is loss of self as cognitive function deteriorates, added to loss of an LGBT identity due to institutionalized cultural incompetence, with the consequence of being rendered doubly invisible. In response to these concerns, in April 2020, the LGBT Foundation secured funding from Homes England for a year-long project to better understand the housing and support needs of LGBT people aged 55+ in Greater Manchester and to involve them in strategic planning, including the country’s first purpose-built LGBT Extra Care Scheme. The report highlighted the evidence that over a third of LGBT people in social housing do not feel safe in their neighbourhood, this includes two thirds of trans people. It also found that nearly 50% of LGBTQ+ people living in social housing do not feel a sense of belonging in their local community and over 25% reported feeling lonely in the area they live.

The report revealed a stark picture in terms of income levels and people's ability to plan and pay for future care. Finally, taking the intersectional, life-course approach advocated by Holman and Walker in considering inequalities in ageing, it is important to note that people embody multiple characteristics (gender, age, ethnicity, health etc), all of which are cumulatively shaped by experiences throughout the life-course. For example, older Irish migrants have poorer physical and mental health than those of the native population. Many of those who migrated to the UK between the 1950-80s suffered from racial prejudice and discrimination, for example with signs on boarding houses saying 'no blacks, no Irish', and did not have access to the same employment and housing opportunities as the local community. Such socio-historical perspectives are necessary to understand attitudes and perceptions around health and illness, and the implications for addressing the complex nexus of often multiple inequalities. It is also important to note that, whilst not planning for the specific needs of diverse communities with dementia can lead to their marginalisation, "narrowly focusing on the distinctiveness of their needs can also create exclusion".

51% would not be comfortable in retirement housing without specific LGBT considerations.

62% had less than £10,000 saved, including 28% who had no savings.

50% said that if they moved into an LGBT Extra Care Scheme they would prefer if it was delivered by an LGBT-specific provider.

74% didn’t know how they would pay for future care and support.

50% said that if they moved into an LGBT Extra Care Scheme they would prefer if it was delivered by an LGBT-specific provider.
Support networks

The evidence in the two exemplars presented here highlight the critical importance for inclusive, identity affirming homes and communities that can meet the diverse needs of different populations and cohorts of older people as these change over time. Such diversity is reflected in the range of informal support networks, including family carers, friends, peers, and neighbours, who are key to living well at home with dementia. For example, research points to the ‘little acts of kindness’ that are frequently and routinely carried out by neighbours and other ‘familiar strangers’ without comment and which enable people to continue to live independently. (35)

It is important to add that any consideration of informal caring and support also must take account of cultural and cohort values, (118) and avoid assumptions about the role of the family, increasing numbers ageing without children and gender bias. The quality and adequacy of housing has enormous impacts for caring, not least on those who may themselves be living with health problems, 22, 39, 119-122). However, a growing body of studies internationally and nationally have linked the pandemic to changes in the prevalence and intensity of informal care, identifying the negative impact on both those living with dementia and their informal carers, not least through increased isolation because of shielding and social distancing. (75, 123-130) However, more work is needed to understand the cultural, social and economic aspects of caregiving for those living with dementia, not least amongst those groups most vulnerable to disadvantage and multiple discrimination. (131)

In the light of the current pandemic, Carers UK has highlighted a number of urgent recommendations to support carers generally, amongst which are the need to:

- Increase awareness and recognition of the role of unpaid carers.
- Ensure that the impact of reduced services on carers and their families are closely monitored in terms of carers’ health and well-being, ability to care, in order to avoid burn-out. Support must be reinstated and restored as soon as possible.
- Raise the level of Carer’s Allowance.
- Ensure that local authorities have sufficient resources to carry out contingency planning with carers. Local government and local partners need to find a way to support carers in delivering this. This must also go hand in hand with effective risk mapping.
- Continue to place a high priority on guidance, information and advice for carers, that adapts to their needs.
- Ensure that if this crisis continues, those unable to work because of caring are continued to be supported to retain their jobs for as long as possible, as well as ongoing flexibility for carers to continue to juggle work and care.
- Increase investment in mental health and wellbeing support for carers.
- Continue to ensure that there are creative ways of supporting carers, through technology, through local communities and with the continuation of key support.
- Ensure that there is sufficient investment in end of life care, death and bereavement services.
- Make social care a priority for funding to ensure that it delivers vital support to people who need it and that the NHS systematically identifies and supports carers. (123)
2. Housing and living well with dementia

The domestic home is the preferred site for care provision for ‘people living with dementia, carers and loved ones’, therefore creating a dementia and caring friendly home environment is crucial. [39]

2.1 Ageing in Place - the meaning of home

Supporting and enabling health improvements within older populations is seen as essential in order to reduce the pressure on public finances. [131]

Providing enabling environments to support individuals of all ages – whatever their physical or mental health - in realizing their potential, and which allow them to participate actively and contribute to their communities throughout their lives, is an urgent policy matter and is key to enhancing quality of life as we age. [9] Central to such environments are the homes in which we live.

The ability to age in place has been highlighted as a major factor in promoting overall well-being in later life. [4, 132] and the majority of us would prefer to stay in our own homes – or move to new homes within our existing communities - as we age. [133-138] Our identities and sense of self are embedded within the places we live and the extent to which they foster independence and autonomy, and support our relationships and inter-personal roles. [136] In terms of health, our attachment to, and familiarity with, our homes can help us develop compensatory strategies in the face of declines in physical and/or mental competencies, [6, 80, 136, 139] because the more we know our environment, the more independent we can be, whatever our level of competence. [140]

Since we tend to spend more time in our home environment as we grow older, it follows that home contributes increasingly to maintaining, or not, our health and quality of life. As Rowles (1993) notes, ‘...older people, particularly as they grow more frail, are able to remain more independent by, and benefit from, ageing in environments to which they are accustomed.’ [26, 141] Ageing in place is also recognised as the most economical way of providing support to people with care needs and is cheaper than nursing home or residential care. [3, 142]

Whilst more work is needed to understand ageing in place over time, [135, 142]; the overall picture is of an emphasis on people ageing in place within their homes and neighbourhood. However, there is growing recognition that ‘there is nothing homely’ about poor housing conditions. [8] Over two- thirds of the buildings and homes we will have by 2050 have already been built. [144] Yet current housing stock in the United Kingdom does not meet the needs of ageing populations and/or those living with dementia. Many people struggle to maintain an acceptable quality of life in their own homes as their dementia advances, often due to the design limitations of mainstream housing, and the challenge of finding affordable domiciliary care and appropriate support services. [145-147]

Given that 18% of pensioners are living in poverty and that pensioner poverty has been increasing over the six years prior to Covid-19 [79]; many older home owners have limited resources to fund improvements to their homes, requiring the support of funds such as the Disability Facility Grants and Dementia Dwelling Grants. Many 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, and 93% of homes lack even basic accessibility features. [148]

In terms of the North of England, the Smith Institute, an independent public policy think tank, highlights the scale of the problem and the increased health impacts of those living in homes that are not fit for purpose. It notes that sub-standard private housing is a major problem and a particularly urgent concern for many older homeowners. Nearly one million owner-occupied homes in the North fail to meet the decent homes standard, in addition to 354,000 private rented homes. Whilst a national problem, it is worse in the North where there are concentrations of pre-war, low value properties, including Greater Manchester.

There have been improvements in housing conditions across the North, notably for social housing (only 9% of social housing is non-decent), but increasingly private homes are falling into disrepair.

Nearly half of all non-decent homes in the North have at least one person with a long-term illness or disability – well above the England average. [149] Furthermore, individuals exposed to poor housing conditions, such as mould, damp and cold, report worse mental and physical health, and experience an 11% increase in doctor visits, increasing to 20% for age groups over 64; and home renovations have been found to significantly reduce doctor visits. [150] This carries considerable costs for the NHS and social care system, as well as negative economic, welfare and environmental impacts. [149] Furthermore, UK Government statistics for the financial years ending 1995 to 2020 show 6% of social renters and 33% of private renters were in poverty, compared to 12% of owner occupiers. [98]

Consequently, the biggest challenge for many older people is not that they themselves are vulnerable but that they live in vulnerable housing situations that leave them precarious, particularly when they are having to cope with mental and/or physical capacity issues. [8] For particular groups of older people such housing vulnerability can be accentuated by health issues, such as dementia and reduced physical capacity, and by reduced financial resources.
Ensuring homes are fit for purpose for everyone presents a major challenge in terms of both commissioning new builds and retrofitting existing stock. (5-7) In response to the increasing awareness of the importance of accessible, affordable housing and healthy ageing, in 2009 the UK government’s Housing and Communities Agency (HCA) sponsored the ‘Housing our Ageing Population: Panel for Innovation (HAPPI)’. In its first report, the panel highlighted the need for: a national effort to build age-friendly homes; the importance of planning ahead, key to which is timely information and advice; and for the availability of a greater range of housing options that could adapt to changing needs, incorporating adaptations and home improvements. It argued that ‘housing for older people should become an exemplar for mainstream housing, and meet higher design standards for space and quality’. It also highlighted the role of Local Planning Authorities in ensuring delivery of ‘desirable housing in great places, tuned to local need and demand’ and the crucial role of Home Improvement Agencies and Occupational Therapists in navigating the system of grants, managing building work etc. A key output from this report was the set of 10 key design criteria. Many are features of good design generally - good light, ventilation, room to move around, good storage, access to outdoor spaces - but they have particular relevance to the spectrum of older persons’ housing, in particular to be able to adapt over time to meet changing needs. (156)

It is worth noting that there is some evidence that the Covid-19 pandemic has sparked what was already a growing interest in alternatives to traditional forms of residential and nursing home care and ageing in place. One option put forward is that of purpose-built retirement communities, which can be seen to offer cohesive and inclusive environments for diverse groups of older people. However, such developments have long been criticised by some commentators as being ‘playpens for the old’, (157) sanctioning the disengagement of older people from wider society, and encouraging the development of aggressively age-conscious identities. (158,159) In addition, there are concerns about social integration and community cohesion within such developments and the extent to which they can offer ‘a home for life’, as many are marketed as doing. (159, 160, 164) Other such options are those of shared and co-housing, which are promising areas of development, with examples existing in Asia, North America, Scandinavia and Europe as well as increasingly in the UK. (165-168) However, not least from a human rights dimension, (9) caution needs to be taken to ensure that such developments remain part of a portfolio of options that promote the autonomy, choices and the social inclusion of people living with dementia, rather than be seen as a one-size fits all. (104, 145, 170)

In its latest All Party Parliamentary report ‘Housing for People with Dementia: are we ready?’, HAPPI makes a number of key policy and investment recommendations to central and local government on dementia-readiness, as well as providing guidance for housing providers. It also states that local authorities should take account of the demand and need for housing for people in their locality living with dementia among minority ethnic groups and LGBT communities, and recommends the establishment of learning and information networks among practitioners to receive and share best practice on housing and dementia.

There is a large body of work on the importance of housing and social conditions, most notably from the Victorians. (171) In his ground-breaking work published in 1957, ‘The Family Life of Older People’, the sociologist Peter Townsend highlighted the continued existence close familial ties amongst older people despite residential segregation. Townsend also confirmed the importance (complexities) of community care in supporting older people in their own homes and preventing hospitalisation and residential care admission. (172) Building on this work, Phillipson and colleagues in 1998 noted the trend towards non-traditional living arrangements, with a move to solo living amongst the white population and the importance of multi-generational living amongst minority ethnic populations. Whilst they observed ‘the enduring importance of family and the significance of friends’ they also noted crucial differences in the ways people maintained contact with members of their networks. (173) Both of these works are part of a large body of evidence-based research over the past 60 years highlighting a complex picture of ageing and home, in which account needs to be taken of the environmental context and its fit for purpose for the individual as well as the impact on families, communities and informal carers.

In addition, in order to ensure quality of life and dignity for people with dementia, their carers and families, the surrounding community needs to provide an inclusive, accessible and enabling environment that optimizes opportunities for health, participation and security for everyone. (35, 38, 42, 48, 174-176)
This recognition of the relationship between our homes and the environments in which they are located is reflected in the growing body of work around ‘age-friendly communities’,[110, 160, 177-179] and ‘dementia friendly communities’. [19, 35, 37, 180, 181] It also resulted in a comprehensive and wide ranging five-year programme of work led by the University of Manchester, comprising of eight work packages framed around people, places and spaces. [182] In 2021 the launch of the Framework for Creating Age-Friendly Homes in Greater Manchester sets an ambition for a permanent cultural shift in thinking around housing in later life. This recognises that older people want a choice of different, affordable mainstream and specialist housing options, that meets both need and aspiration and in places where they can maintain or build social connections, achieve good health and independence.

Such work on social engagement and environmental support emphasises the ‘capabilities, capacities, and competencies’ of people living with dementia [35] and the active roles they can and do play in the ‘ongoing production and maintenance’ of their neighbourhoods as relational spaces that enable them to carry out reciprocal acts of support and remain engaged. [35] Clarke and colleagues argue that such social engagement can offer a ‘metaphorical safety net of support’ to call on should the need arise, and which echoes the three dimensions to living well with dementia identified by Austin et al of “Social Flourishing, Contentedness and Safety-Security”. [19] In keeping with the literature on reducing stigma, such engagement also acts as a means of raising awareness of the condition. Fundamental to such an approach is person-centred care. When this is adopted systematically, including at an organisational level, it has been found to directly increase the quality of life of people living with dementia, and potentially improve well-being and reduce neuropsychiatric symptoms, maintaining dignity and personhood. [183]

To ensure quality of life and dignity for people with dementia, their carers and families, the surrounding community needs to provide an inclusive, accessible and enabling environment that optimizes opportunities for health, participation and security for everyone.

[https://greatermanchester-ca.gov.uk/what-we-do/ageing/creating-age-friendly-homes-in-greater-manchester/]
**Part 2. Greater Manchester system wide analysis**

**Introduction**

In this section we provide a system-wide analysis mapping provision across Greater Manchester with a gap analysis covering medium and long-term need. The mapping was carried out through an iterative process of gathering GM available data (with the advice of the Data Lead for GMHSCP), engaging with on-going local and national initiatives around housing and care, and sharing emerging findings with a range of stakeholders.
Stakeholder Engagement

Evidence for this report sought to bring views and experiences from stakeholders spanning the ten boroughs of Greater Manchester, an array of neighbourhoods each with their own socio-economic characteristics.

From June 2020 GMHSCP engaged with social housing providers, architects and developers experienced in the field, supporting Greater Manchester Housing Providers in a joint submission to the APPG on Housing for People Living with Dementia’s Call for Evidence. At the same time, we began to build up an understanding of key issues affecting people living with dementia and their carers through lived experience groups. The Dementia Carers Expert Reference Group provided a steer on key issues following a ‘deep dive’ into housing at a meeting in October 2020, and through presentations and discussions with the Dementia United Strategic Board.

From February to March 2021, GMHSCP and the University of Manchester held in-depth meetings with GPs, Nurses, Local Authority Housing Leads, alongside national policy leads. In April and May the report’s findings were drafted across seven themes, ranging from housing support in dementia care; planning and development; and building a community of practice. The Greater Manchester Ageing Hub, and in particular stakeholders at the Housing, Planning and Ageing Group, have been key in placing this report and its recommendations within a wider policy landscape. In June 2021, discussions were held with the strategic housing and health and social care leads across the ten districts of Greater Manchester on the emerging findings of the report, exploring current best practice and gaps in what was currently available. Lived experience of staff from across the housing sector has also been crucial in examining issues facing tenants with dementia and some of the challenges it can present landlords. From August to November 2020 GMHSCP conducted a series of focus groups with frontline housing association staff, including operational managers, neighbourhood officers, maintenance workers and staff engaged in customer support from across Greater Manchester.

Lived experience of staff from across the housing sector has also been crucial in examining issues facing tenants with dementia and some of the challenges it can present landlords. From August to November 2020 GMHSCP conducted a series of focus groups with frontline housing association staff, including operational managers, neighbourhood officers, maintenance workers and staff engaged in customer support from across Greater Manchester.

Summary of Stakeholder Engagement
Strategic Boards and Experts by Experience Consultations and Engagement

<table>
<thead>
<tr>
<th>Details</th>
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<th>Date</th>
</tr>
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<tbody>
<tr>
<td>Dementia United Strategic Board</td>
<td>15</td>
<td>Recurrent bimonthly meeting with regular reports on dementia and housing, updating project goals (engagement from September 2020)</td>
</tr>
<tr>
<td>Dementia Carers Expert Reference Group: Meeting of carers of people living with dementia from across Greater Manchester, working with Dementia United programme on key themes, for example post-diagnostic support, delirium, housing</td>
<td>7</td>
<td>12 October 2020</td>
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<tr>
<td>GM Mental Health and Housing Group Steering Group: mental health trusts, commissioners, housing providers, voluntary, community and social enterprise (VCSE) sector partners</td>
<td>15</td>
<td>Recurring meeting focused on various housing and mental health projects across Greater Manchester (monthly from April 2020 moving to bimonthly from January 2021)</td>
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<tr>
<td>GP in South Manchester, with specific interest in Dementia in Greater Manchester</td>
<td>1</td>
<td>22 July 2020; 25 February 2021</td>
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<tr>
<td>Salford Institute of Dementia Lived Experience Group</td>
<td>6</td>
<td>Meetings to discuss housing issues with people living with dementia and their carers 27 May 2020; 6 July 2020</td>
</tr>
<tr>
<td>Greater Manchester Housing Provider Health Steering Group. Regular meeting of Greater Manchester social housing providers with a particular focus on the links between health and housing, led by Mosscare St Vincent’s housing association</td>
<td>15</td>
<td>Two Mental Health themed sessions on 14 September 2020; and 13 October 2020</td>
</tr>
<tr>
<td>Living Well at Home Market Shaping meetings: local authorities, care providers (nursing/resident &amp; home care) and GM staff</td>
<td>20+</td>
<td>Recurrent meeting discussing various issues around ASC market-shaping 29 September 2020; 25 November 2020; 22 December 2020</td>
</tr>
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</table>
### Engagement and Consultations

This included housing association frontline workers, operational managers, neighbourhood officers, maintenance workers and staff engaged in customer support.

<table>
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<tr>
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<tr>
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<td>Great Places</td>
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<td>Trafford Housing Trust</td>
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<td>For Housing</td>
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<tr>
<td>Jigsaw Homes (Consultation 1)</td>
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<tr>
<td>Jigsaw Homes (Consultation 2)</td>
<td>4</td>
<td>10 October 2020</td>
</tr>
<tr>
<td>Stockport Homes (Consultation 1)</td>
<td>4</td>
<td>8 October 2020</td>
</tr>
<tr>
<td>Stockport Homes (Consultation 2)</td>
<td>3</td>
<td>10 October 2020</td>
</tr>
<tr>
<td>Webinar for GM Social Prescriber Link Workers</td>
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<td>22 March 2021</td>
</tr>
<tr>
<td>Local Authority Strategic Housing Lead</td>
<td>1</td>
<td>23 February 2021</td>
</tr>
<tr>
<td>Consultation with Greater Manchester Housing Strategy and Dementia Leads</td>
<td>20</td>
<td>June-July 2021</td>
</tr>
<tr>
<td>Arc4 meeting – realising GMCA + partners ambitions for housing in later life around planning for an ageing population</td>
<td>2</td>
<td>2 March 2021</td>
</tr>
<tr>
<td>Alzheimer’s Society - Meeting with regional and national policy leads at Alzheimer’s Society with remit including housing for people living with dementia</td>
<td>2</td>
<td>4 March 2021</td>
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<tr>
<td>Wigan Dementia Strategy Task Group - Operational group monitoring the implementation of Wigan’s dementia strategy</td>
<td>8</td>
<td>19 March 2021</td>
</tr>
<tr>
<td>Better Homes, Better Neighbourhoods, Better Health: Tripartite Agreement Launch - including senior NHS, LA and housing association staff, press, people with lived experience of care</td>
<td>100+</td>
<td>23 March 2021</td>
</tr>
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</table>

### Why Now? Adult Social Care markets in light of Covid-19

Covid-19 has thrown the issue of market shaping into sharp relief. Adult Social Care (ASC) commissioners have an opportunity to take stock with communities as to how or if local housing offers meet residents’ needs in terms of the domains highlighted in the review, and the extent current approaches promote the Care Act (2014) principles of individual wellbeing, choice and control. (184)

Across Greater Manchester, local authorities commission and provide a range of services to support people to maintain or regain their independence after a period of ill health at home, or a hospital stay. In August 2020, ASC supported around 50,000 people across the ten districts of Greater Manchester, including in care home settings. This was in addition to providing a combination of home care, reablement, supported housing, respite, day services and personal budgets to support people to live independently at home. There are 60,000 people employed as staff in care home or care at home settings across the city-region. Across a range of needs, including for people living with dementia, local authorities spend circa £713m in the care home market each year. (185) Reablement support in particular is commissioned with the intention of improving independence and quality of life, reducing the size of longer terms packages of care, reducing long term admissions to care homes and reducing inappropriate readmissions to hospital. Provision in this area is increasing, with £179m spent on reablement provision in 2017/18, compared to £19.3m spent in 2018/19, and an additional £3.1 and £4.8m spent on other related short-term support in the same periods.

This support, aimed at assisting people to maintain an independent life in their homes, is framed within a context of significant long-term cuts to funding. Over the past decade in Greater Manchester, government spending on Adult Social Care (ASC) fell in real terms by about £300m despite a 21% rise in the number of citizens aged over 65 (internal document – verified by Data Lead at GMHSCP). For residential and nursing care, there are long standing challenges for market sustainability that the Covid-19 pandemic has only exacerbated. This report examines this issue in particular, before turning to the mainstream and specialised housing offer in Greater Manchester, arguing for an immediate need to shape the market to offer more housing choice and diversity for people living with dementia and their carers.
A number of key points were echoed in discussions with stakeholders on what the future commissioning of a diverse housing offer for people living with dementia should include:

Commissioners must work collaboratively to commission effectively and shape the market within a stark financial environment, guided by an understanding of what people want and need from services.

- Build on collaborative and integrated work across health and social care so people get the right support and funding without navigating complex systems, with multiple hand-offs.
- Identify plans to decommission housing options that constrain independence and re-invest in mainstream and supported housing options that focus and support asset-based solutions.
- Investment in sustainable innovation that improves outcomes, including enhanced individual and community resilience, and better value for money.
- Community mobilisation has been a positive feature during Covid-19 – the voluntary and community sector (VCSE) and mutual aid groups are central to the planning for recovery as well as the longer term. How these can be linked in to housing support, for example through social prescribing teams, is a significant opportunity.
- Carers are essential to recovery plans and need access to support for their own health and housing advice.
- Invest in enablers that help people live well and be socially connected and included, such as digital devices and skills, accessible design and assistive technology.

We often make assumptions about where people want to live in their later life. Whether it’s rightsizing to a more manageable property or moving into a retirement community, many of us paint a mental picture of ‘housing for older people’ without thinking. The reality, though, is very different: the vast majority of older people live in ordinary, mainstream homes, and they have absolutely no intention of changing that.

Andy Burnham, Mayor of Greater Manchester, 2018 (188)
## Type and tenure

### Mainstream Housing
- **Individual Homes to buy or rent** – not designed for any specific user group though Lifetime Homes include ‘age-friendly’ features and wheelchair housing is specifically designed. Personal care, support, other services and amenities available within the community.
- **General Needs** – Housing with no specialised features.
- **Lifetime Homes** – Housing designed to meet access and adaptability standards for everyone including older people.
- **Adapted Homes** – Housing which has been changed to meet the needs of its residents.

### Supported Housing
- **Groups of homes (usually flats) to buy or rent** – designated for older people (typically 55+)
  - Personal care and support usually arranged or provided within the development together with shared facilities and activities.
  - **Sheltered/Retirement** – Independent Living (own front door) may include 24-hour alarm system, warden, lounge, programme of activities.
  - **Very Sheltered/Assistive Living** – Independent living with managed care and support services. Features as above, may also include: meals, domestic help, assisted bathing.
  - **Extra Care** – Independent Living with managed onsite care and support services. Features as above, may also include hairdressing services, 24 hour staff.
  - **Close Care Housing** – Independent living with on-site care and support, linked to a care home.
  - **Retirement Villages** – Large developments (often 100+) with a range of housing types and levels of care and support (sheltered, very sheltered/extra care, close care and nursing care) on one site.

### Residential Care or Care Homes (rather than independent living)
- **Institutional accommodation (suites of bedrooms) with care services and facilities**
- **Retirement Villages** – accommodation with meals, person care (physical and emotional), staff on call.
- **Nursing Homes** – Care Homes with 24 hour nursing care.
- **Specialised Care Homes** – Care Homes.

One-third of all one-bedroom properties are occupied by people over 65. This figure is highest in Oldham but lowest in Manchester, where one-bedroom properties tend to be marketed towards young professionals within the private rented sector, and the number of people living alone increases with age (table on the next page). This trend is particularly pronounced in Oldham where for those aged 55 to 59 26.6% are one person households, rising to 74.3% for those aged over 85.

**Source:** Barac, M. & Park, J., 2008. HAPPI. Housing our ageing population: Panel for innovation, s.l.: Gov.uk.
Table: Number of people living alone by age

<table>
<thead>
<tr>
<th>Area</th>
<th>Aged 55-59</th>
<th>Aged 60-64</th>
<th>Aged 65-74</th>
<th>Aged 75-84</th>
<th>Aged 85+</th>
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<tbody>
<tr>
<td>Bolton</td>
<td>28.1%</td>
<td>33.5%</td>
<td>40.4%</td>
<td>55.1%</td>
<td>71.7%</td>
</tr>
<tr>
<td>Bury</td>
<td>27.6%</td>
<td>32.2%</td>
<td>40.3%</td>
<td>53.5%</td>
<td>70.4%</td>
</tr>
<tr>
<td>Manchester</td>
<td>38.8%</td>
<td>46.2%</td>
<td>51.3%</td>
<td>57.8%</td>
<td>67.9%</td>
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<tr>
<td>Oldham</td>
<td>26.6%</td>
<td>33.2%</td>
<td>41.9%</td>
<td>56.9%</td>
<td>74.3%</td>
</tr>
<tr>
<td>Rochdale</td>
<td>30.0%</td>
<td>35.8%</td>
<td>42.3%</td>
<td>56.2%</td>
<td>72.3%</td>
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<tr>
<td>Salford</td>
<td>35.6%</td>
<td>40.1%</td>
<td>44.7%</td>
<td>58.1%</td>
<td>73.2%</td>
</tr>
<tr>
<td>Stockport</td>
<td>27.2%</td>
<td>31.8%</td>
<td>40.0%</td>
<td>53.3%</td>
<td>68.3%</td>
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<tr>
<td>Tameside</td>
<td>30.0%</td>
<td>34.6%</td>
<td>43.0%</td>
<td>56.7%</td>
<td>72.9%</td>
</tr>
<tr>
<td>Trafford</td>
<td>25.9%</td>
<td>32.6%</td>
<td>39.9%</td>
<td>52.6%</td>
<td>68.4%</td>
</tr>
<tr>
<td>Wigan</td>
<td>26.6%</td>
<td>30.7%</td>
<td>36.6%</td>
<td>52.4%</td>
<td>71.0%</td>
</tr>
<tr>
<td>Greater Manchester</td>
<td>30.0%</td>
<td>35.3%</td>
<td>42.0%</td>
<td>55.1%</td>
<td>70.7%</td>
</tr>
</tbody>
</table>

Source: Office of National Statistics, National Census 2011 (189)

Of properties occupied by those aged over 65 across Greater Manchester, 48.8% have two or more spare bedrooms and, while this is lower than the North West (51.8%) and England (51.6%) as a whole, it represents a significant proportion of older persons housing. Under-occupancy for those aged over 65 is lowest in Oldham at 39.5% and highest in Trafford (59.9%).

The majority of those over 65s tend to be owner-occupiers, with the majority of those owning their home outright. Unlike social or private rented tenants, home-owners have sole responsibility for funding and arranging any repairs, adaptations, or changes. This can cause challenges for people living with dementia as their condition progresses.

For people aged over 65, data reflects a considerable reliance on the social rented sector in Greater Manchester when compared with national and regional benchmarks. Over 25% of residents in Greater Manchester rely on social housing (25.6%), a higher proportion when compared with national and North-West averages (19.8% and 20.2% respectively). (187, 192)

Due in part to rising house prices, stagnating wages and the inability to rent in the social housing sector, more people are relying on the private rented sector. Although the number of people aged 65 and older living in the private rented sector is relatively small at present, there is still an estimated 750,000 renters in England over the age of 65. This number is expected to grow as younger and middle-aged tenants move into the sector in the coming decades, unable to buy a property or access social housing.
Supported Housing

There is no single set of planning guidelines on what supported housing should be, however there is a growing consensus of good design principles that support people living with dementia in a person-centred way.

Well designed specialist housing can provide communal spaces where group activities can take place such as: intergenerational activities, efforts to promote digital access and partnerships with local outreach organisations. Crucially, they can also support carers in respite and allow opportunities to live outside of their caring responsibilities for a few hours or longer.

Specialist housing can result in reduced social care spending due to care package reductions, equipment, community alarm systems, and residential care costs. In 2017, research from North West Association of Directors of Adult Social Care Service (NWADASS) highlighted how a ‘standard’ extra care scheme, when compared to low level residential care packages, released a saving of approximately £6.7 million per year across Greater Manchester, as the tables across demonstrate. In Greater Manchester, there is a growing shortfall in supported housing designed for older people, despite the benefits this could offer.

Table: Cost-Benefit Analysis on Extra Care Packages compared to Low-Level Residential Care Packages

<table>
<thead>
<tr>
<th>Local Authority</th>
<th>Cheapest 10% Residential Service Users</th>
<th>Average Weekly Cost of these 10%</th>
<th>Annual Cost of These Placements Currently</th>
<th>Est Extra Care Package (based on 14 hrs per week @ £13.50ph)</th>
<th>Cost Difference per Year</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bolton</td>
<td>60</td>
<td>£436.69</td>
<td>£1,362,468</td>
<td>£589,680</td>
<td>£772,788</td>
</tr>
<tr>
<td>Bury</td>
<td>54</td>
<td>£411.24</td>
<td>£1,154,764</td>
<td>£530,712</td>
<td>£624,052</td>
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<tr>
<td>Manchester</td>
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<td>£390.06</td>
<td>£1,176,414</td>
<td>£570,024</td>
<td>£606,390</td>
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<tr>
<td>Oldham</td>
<td>66</td>
<td>£404.08</td>
<td>£1,386,818</td>
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<td>£738,170</td>
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<tr>
<td>Rochdale</td>
<td>58</td>
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<tr>
<td>Salford</td>
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<tr>
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<tr>
<td>Tameside</td>
<td>55</td>
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<td>£1,245,059</td>
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<tr>
<td>Trafford</td>
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<td>£640,598</td>
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<td>£345,758</td>
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<tr>
<td>Wigan</td>
<td>71</td>
<td>£410.89</td>
<td>£12,520,744</td>
<td>£5,759,208</td>
<td>£6,761,536</td>
</tr>
<tr>
<td>GM Total</td>
<td>586</td>
<td>£410.89</td>
<td>£12,520,744</td>
<td>£5,759,208</td>
<td>£6,761,536</td>
</tr>
</tbody>
</table>

Source: NWADASS 2017 (191)
As the Table shown reflects, this shortfall amounts to an additional 8,500 units of supported housing for older people across the ten districts by 2035. At a district level, Wigan and Stockport are projected to have the highest number of property shortfalls by 2035 at over 1,000 each. In Wigan this is fairly evenly split between properties to rent and properties to lease. In Stockport the projected shortfall includes more properties for lease rather than rent, which is also the case in Trafford and Bury. Oldham and Rochdale, however, have more of a shortfall for rent (both 621) rather than to lease (193 and 221 respectively).

Table: SHOP@Predictive Modelling – Housing with a Care Need

<table>
<thead>
<tr>
<th>Area</th>
<th>2020</th>
<th>2025</th>
<th>2030</th>
<th>2035</th>
<th>Shortfall 2035</th>
</tr>
</thead>
<tbody>
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<td>9013</td>
<td>9912</td>
<td>10976</td>
<td>8561</td>
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<tr>
<td>Bolton</td>
<td>833</td>
<td>1019</td>
<td>1124</td>
<td>1239</td>
<td>915</td>
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<tr>
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<td>585</td>
<td>714</td>
<td>777</td>
<td>858</td>
<td>656</td>
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<tr>
<td>Manchester</td>
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<td>942</td>
<td>1056</td>
<td>1187</td>
<td>650</td>
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<tr>
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<td>837</td>
<td>921</td>
<td>815</td>
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<tr>
<td>Rochdale</td>
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<td>714</td>
<td>798</td>
<td>886</td>
<td>843</td>
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<tr>
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<td>609</td>
<td>711</td>
<td>767</td>
<td>854</td>
<td>543</td>
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<tr>
<td>Stockport</td>
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<td>1232</td>
<td>1344</td>
<td>1477</td>
<td>1091</td>
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<tr>
<td>Tameside</td>
<td>672</td>
<td>826</td>
<td>910</td>
<td>1022</td>
<td>866</td>
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<tr>
<td>Trafford</td>
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<td>924</td>
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<td>1260</td>
<td>1376</td>
<td>1498</td>
<td>1348</td>
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</table>

Source: GMHSCP 2019 (187, 192)

Table: SHOP@Predictive Modelling – Sheltered/Retirement Housing

<table>
<thead>
<tr>
<th>Area</th>
<th>2020</th>
<th>2025</th>
<th>2030</th>
<th>2035</th>
<th>Shortfall 2035</th>
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<tr>
<td>Rochdale</td>
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<tr>
<td>Stockport</td>
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<td>4,800</td>
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<td>2400</td>
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<tr>
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<tr>
<td>Wigan</td>
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<td>4500</td>
<td>4913</td>
<td>5350</td>
<td>3,306</td>
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</table>

Source: GMHSCP 2019 (187, 192)
Case Study 1

Specialised Supported Housing in Wigan

Wigan Council have a Specialist Housing Panel that considers needs and opportunities for specialist housing in the borough. Made up of officers and commissioners from across the Council who have an interest in ensuring that supported and specialist housing in the borough is high quality, the Panel has been established to review, recommend and support proposals made to the Council for the provision of new specialist housing schemes, and monitor the strategic provision of supported and specialist housing services across the borough.

The panel is designed to:

- Review proposals for new specialist housing schemes, identifying key strategic and operational benefits and risks.
- Ensure a consistent, considered, and strategic approach to the consideration of new scheme proposals from potential partners.
- Support the aims and objectives of the Homes for All agenda, a key priority within Wigan’s plan for the Future, Deal 2030.
- Secure confidence in the suitability and viability of new schemes and developments to help our residents Start Well, Live Well, and Age Well.

Any expressions of interest from potential partners in providing specialist housing services are triaged and scrutinised by the Panel to ensure that proposals comply with the aims and objectives of the Specialist Housing Prospectus, wider Housing Strategy, and requirements identified by our Housing Needs Assessment, along with meeting identified demand and accommodation and care standards.

Partners are asked to consider how any proposed scheme meets the needs set out in this prospectus (for particular client group/s), and will need to provide information pertaining to funding, land, scheme layout and design, physical/social/environmental impacts, support required from the Council, and other factors.

Wigan’s online ‘Developer Hub’ contains special information for developers and housing providers looking to bring forward supported and specialist housing schemes. An online form designed to capture the information necessary for the Specialist Housing Panel to make an informed decision as to whether to support and bring forward a new proposed specialist housing scheme. A similar approach has also been put into practice by Rochdale Council.

In Greater Manchester, around 1 in 20 households are in overcrowded accommodation, disproportionately concentrated in the rented sector.
Quality and Inequality

Even before the pandemic, Greater Manchester was fractured by inequalities in health and wellbeing, cutting across localities, ethnic groups, age and gender, with GM too often falling below national averages.

Housing inequality is a powerful symbol of this, driving and entrenching socio-economic inequalities between different groups and different areas within the city-region.

In Greater Manchester, around 1 in 20 households are in overcrowded accommodation, disproportionately concentrated in the rented sector. Conversely, two-thirds of households (and 80% of owner-occupiers) have at least one spare bedroom, according to the official definition. (195)

Shielding during the pandemic, and self-isolating, has been more challenging for people living in larger, more over-crowded households. This has been a particular issue for multi-generational households, and notably those with older family members; this is more common for people of Pakistani, Bangladeshi and Indian ethnicity, reflected in the higher death rates among South Asian older women who live with younger people.

From the range of stakeholders, including people with lived experience of dementia in Greater Manchester, there was a strong aspiration for making small practical adjustments to maintain independence as well as making some of the larger scale adaptations.

However it must be recognised that this is not possible for many people and communities, for financial reasons or because homes are small, particularly in smaller terraced housing with narrow corridors and steep staircases (one fifth of all properties in Greater Manchester are pre-1918 terraced stock). There are widespread concerns about the quality of homes in the private rented sector, particularly within those parts of Greater Manchester with concentrations of pre-war, low value properties, notably the terraced housing in and around the Pennine town centres.

The importance of communities that have been historically marginalised, and continue to experience stigma and discrimination lacking voice and agency in decisions around housing options that support people and communities to stay connected after a diagnosis of dementia was also highlighted. The example in Case Study 2 in Manchester provides some important lessons in this respect.

Case Study 2

First LGBTQ+ Extra Care Scheme in Manchester

Manchester’s older LGBT population is growing. There are more than 7,000 people in Manchester over the age of 50 that identify as LGBTQ+ and this figure is expected to rise over next two decades (Exemplar 2 for details). The Council has been working closely with the LGBTQ+ Foundation to develop the core principles of an innovative project delivering more than 100 apartments for people aged 55+: how it should operate and what care should be available onsite to support LGBTQ+ people as they get older. Once the right site was acquired the Council and LGBTQ+ Foundation worked to develop strong relationships with the local community to help guide the scheme. A Community Steering Group was set up in 2020 with the aim of co-producing the principles of the scheme and agree design concepts that will complement the local area.

Housing association Anchor Hanover were chosen to develop the scheme following a competitive process. They were selected after demonstrating their experience in delivering similar projects across England, including New Larchwood, an LGBT+ inclusive retirement housing scheme in Brighton, and showed an ambition to create a facility that meets the needs of the city’s LGBTQ+ community.

Cllr Bev Craig, Leader of Manchester City Council, said:

“Manchester was proud to be the first place in the country to announce such a scheme so it’s great to see this scheme come to fruition. Our ambition came on the back of years of research and engagement with older LGBTQ+ people. We’ve been working closely with the LGBTQ+ Foundation and local people for some time to ensure the site, location, the principles of the scheme, and eventual design principles work – both for the LGBTQ+ community, but also for the local people in Whalley Range…We already know LGBTQ+ people are more likely to be lonely later in life, and as this community is growing, it shows that this Extra Care is not only welcome but absolutely needed.”
These recommendations seek to achieve a permanent shift in housing options for people living with dementia and their carers in all ten districts of Greater Manchester.

The Future of Commissioning for Social Care’, Social Care Institute of Excellence

Following an overview of demographic trends, the health and social care market, mainstream and specialised housing, this report makes seven recommendations around:

1. Accessible Guidance and Information
2. Integrated Pathways
3. Planning Ahead
4. Market-Shaping
5. Combating Stigma
6. Knowledge mobilisation and implementation
7. Evidence-based policy and practice

The timeframe for implementing the seven recommendations is three years through a targeted Implementation Plan (see next steps), but the ambitions are longer-term. Taken together, these recommendations seek to achieve a permanent shift in housing options for people living with dementia and their carers in all ten districts of Greater Manchester. Such a shift emphasises independent living, the right to a flourishing life, and choice and control, driven by the voices, experiences and aspirations of citizens.
Recommendation #1
Accessible Guidance and Information

Independent housing information and advice for people who receive a diagnosis of dementia, their families and carers.

People living with dementia and their carers should have readily available guidance on several key issues:

- Making simple adaptions to the home;
- How assistive technology can support;
- Issues around ‘rightsizing’ or moving into supported accommodation;
- Funding options for adaptions;
- Activities that support people to articulate what ‘home’ means to them, what is important to cultivate a sense of security and belonging.

All such advice and guidance needs to be in a range of formats, culturally sensitive and in line with best practices in supporting health literacy, particularly in the light of the IMF findings that people in the UK have the lowest literacy and numeracy skills in Europe.

The context in which assessments are made also has an enormous impact. Often important conversations around housing and the home take place as a result of crises or change of circumstances, for example a fall. Ensuring important information on healthy homes can mediate physical frailty and/or mental ill health and reduce hospital admissions; it can enable timely discharge from hospital and delay or avoid unwanted moves to residential care or more specialist housing; all of which also create enormous social and public savings benefits.

Although there is no one size fits all approach, the timeliness of advice and guidance is important, so people can plan ahead. The Local Government Association advise 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 need. Early discussions and planning with people living with dementia and their families and loved ones is essential, putting necessary processes in motion before a point of crisis is reached.

Dedicated time within post-diagnostic pathways would encourage people to think about their housing needs whilst they are still able to make positive choices.

Carers

The needs and wishes of carers may differ from those of the people they care for. Carers need access to information and advice and the opportunity to reflect on whether they are going to be able to manage in the longer term in their existing accommodation. Carers would benefit from such discussions within a post-diagnostic support programme and the right to an assessment of need in their own right was re-affirmed in the Care Act 2014.

Conversations around housing need to bring in the views and desires of carers, recognising the wider social support systems they draw strength from. These could be family or friends that live locally and may be vital lifelines of emotional support, social contact, and informal respite arrangements (even for just a few hours). There are major implications for the carer in thinking about whether to move home which must be considered alongside those for the person with dementia. This is particularly important in circumstances when the main responsibility for organising care lies with the carer.

Carers need access to information and advice and the opportunity to reflect on whether they are going to be able to manage in the longer term.

---
Evidence points to areas of good practice in Greater Manchester when residents seek housing advice and support after a diagnosis of dementia, however this is not consistent across the ten local authorities and there is no agreement on when and what information should be provided as a standard offer.

A Housing Options for Older People (HOOP) service, established and led by Greater Manchester Housing Providers, offers advice and support for older people to understand their housing options and potentially move to a more appropriate home. The service generally comprises two stages: an assessment of the person’s current housing situation, and the provision of information and advice on alternative options. This may then lead to support with adapting their current home or moving to a more appropriate home to meet their needs. In Greater Manchester, six districts currently have HOOP officers in post: Bolton, Manchester, Rochdale, Salford, Stockport, Wigan. In Tameside and Trafford there is a designated officer within the Housing Options service who works with older people; in Bury this service is provided via another team in the Council, and in Wigan Age UK provide this service.

Similarly, Handy person or Home Improvement Agencies (HIA) services generally provide low level home improvement work, aiming to enable older and disabled people to live well in their own homes for longer, including but not limited to:

- **Small repairs** - such as putting up shelves, changing lightbulbs
- **Safety measures** - such as fitting smoke alarms or grab rails
- **Home security** - such as fitting door and window locks
- **Energy efficiency checks** - such as installing draught excluders, radiator heat reflectors and energy efficient lightbulbs.

Local authorities also rely on VCSE partners, often those with strong local links to the community. In Bolton, Bolton Dementia Support (BDS) has a dementia care navigator who helps people find support, practical help and access groups and activities that can help them live independently. As part of this person-centred offer, BDS links in with Age UK to provide services such as help at home, (practical support to maintain independence) and befriending, open to all older adults local and national ageing well aspirations.

In Oldham, a contract between Oldham Cares and Age UK provides a drop-in housing advice service and a post-diagnosis dementia navigator service that looks at the person’s housing and offers advice on issues. At the same time, Making Space provide post-diagnostic support in the community through peer support group, including housing advice. Housing Options Service within Oldham Council acts as the central point of contact for supporting people with dementia who potentially need specialist accommodation. Understanding what works well locally and how different offers complement or duplicate each other is essential in providing a clear, consistent offer for Greater Manchester residents, no matter where they live.
Recommendation #2
Integrated Pathways

Ensuring housing is integral at every stage of the dementia care pathway in Greater Manchester, including care strategies.

A wide range of health and social care practitioners including dementia advisors, care navigators, and social prescribing link workers provide information and advice to people affected by dementia. However, evidence points to a lack of awareness and training on housing needs. Such awareness and training needs to include how best to support people at all stages of the pathway as their housing needs change, and address issues of stigma and discrimination. It is important that these conversations do not focus solely on moving from current living arrangements and that other options, for example those available through HIAs, are fully explored.

A rights-based approach should be used to in assessing and managing risks. Advocates of people living with dementia and their families have highlighted the underlying power dynamics in these relationships. Creating a culturally sensitive environment to explore all options within which the individual concerned feels able to articulate their preferences honestly, without worrying about what responses they may get, is crucial.

For people who lack mental capacity, Best Interest Decisions are required in some circumstances, not least in signing legal documents. Staff working within the principles of the Mental Capacity Act (2015) must make sure they find out as much as they can about the individual’s known wishes and aspirations and living circumstances. Using a rights-based approach enables a balanced appraisal by all involved of the risks in remaining at home and being admitted to residential care.

The contribution of social housing staff to discharge planning can also be overlooked (as discussed previously, around one quarter of residents in Greater Manchester over the age of 65 live in social housing). Although social housing providers have valuable information about individuals and how they were managing at home, focus groups with frontline housing officers from across Greater Manchester confirmed that they are rarely involved or regarded as informed professionals by health and social care colleagues.

Key teams

**Hospital Discharge Teams**

Staff are crucial in shared decision making about whether an individual with dementia returns home after a hospital stay. The significance of ‘home’ for patients may not be known to staff. It follows that opportunities should be created for people to discuss what matters to them in relation to the home – both the place and the people – so that appropriate help and advice can be offered.

Assumptions may be made about what sheltered or extra care housing provide without checking with housing staff, so people may be discharged inappropriately. Discharge teams should work with housing staff as equal partners and involve them in planning.

Discharge teams should be up to date on:
- Local housing and support options
- Access to these options
- Changes in benefits linked to housing
- Eligibility criteria for Disabled Facilities Grants

**Social Care Assessors**

Exploration of housing during the assessment process should include information about all possible options and social care assessors should be familiar with the expectations and requirements of housing providers available within the local neighbourhood. Assessors should also be able to point people in the right direction for advice on legal and financial matters. Occupational therapists have a particular role to play, given their attention to maintaining activities of daily living and their expertise in assessing how well people manage in their physical environments.

**Housing Staff**

Some housing providers have well established systems and procedures for all these stages, whereas others gave less attention to the application stage and only initiated detailed discussions at the point an offer is made. Account needs to be taken of the fact that some families/carers feel the need to disguise the extent of their relative/loved one’s dementia for fear of jeopardizing the offer, posing a risk that people may move into accommodation that is not best suited to them. Similarly, difficulties may be masked in the person with dementia by their care-giving spouse or partner and may only become apparent when the caregiver themselves is no longer able to provide care for whatever reason.
Recommendation #3
Planning Ahead

Ensuring post-diagnostic support programmes offer opportunities to explore housing options as well as financial and legal planning. Through our planning departments, identifying clear requirements for dementia-ready housing, including those from minority communities. We allocate ‘suitable sites’ (e.g. in town centres), identified in conjunction with local housing and care providers specifically for age-friendly housing.

Those undertaking social care assessments should introduce the topic of housing needs at the earliest opportunity. Sometimes referrals for supported housing come too late when people’s needs have become more complex and the most likely outcome is residential care.

Homes need to be accessible, adaptable and technology-enabled. They must take account of existing recommendations, be adaptable, safe, warm and in established and vibrant neighbourhoods, recognising the importance of attachment to place and social connections. Local Authority Planning Departments, working with Housing Strategy leads and local housing providers are crucial in building better homes, better neighbourhoods and better health.

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 appropriate housing and inclusive communities. Greater clarity on the planning policy for inclusive 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 mainstream and specialist housing, providing more choice and diversity for people living with dementia.

A major challenge is the identification of suitable and affordable land, especially in an urban setting. The development of new properties for older people could also be stimulated by refocusing some of the requirements of Section 106 and the Community Infrastructure Levy.

Recommendation #4
Market-Shaping

Through our housing strategy teams, we recognise the growing demand for social and private rented housing for those currently living with dementia in unsuitable homes.

Housing choices across Greater Manchester for people living with dementia, indeed for all residents in mid to later life, are diverse. Housing strategies should be underpinned by person-centred care, respond to different needs and aspirations, promote social connections and support equality, positive health, well-being and independence, and in line with current guidance.

The majority of people will remain living in their current home as they age, but others will want to or will need to move. There will be people who live independently all of their lives, whilst some will need accommodation with access to specialist care and support to maintain their independence.

Shaping local markets has a remarkable impact on people’s health and wellbeing. The Care Act has given local authorities a duty to shape the care market to meet the needs of their local populations. This includes working collaboratively to promote housing choice local communities through their commissioning strategies.

As discussed in previous sections, providing a range of housing options is an essential part of the platform on which neighbourhoods can thrive, where people can live well, maintain social connections and create positive futures.
Recommendation #5

Combating Stigma

A range of measures should be put in place to address discrimination and stigma, including raising awareness of ageism, racism and LGBTQ+ issues.

Such measures should include creating identity affirming spaces that support the visibility of those living with dementia and enable social connection and engagement. A key focus should be an emphasis on person-centred care, and supporting the autonomy, resilience and agency of those living with dementia and their carers.

People who use services often point to basic quality standards as missing – respect, courtesy, communication, and reliability. Key to addressing this is developing and supporting cultural competence amongst health and social care practitioners and organisations so that people living with dementia and their carers feel valued, understood and able to express their aspirations, fears and needs in order to identify appropriate and acceptable housing options.

Recommendation #6

Knowledge Mobilisation and Implementation

To support rapid and wide dissemination and implementation, a knowledge mobilisation framework should be developed in consultation with a wide range of stakeholders through the establishment of a community of practice (COP).

The COP should consist of people living with dementia and their carers, primary and secondary health and social care practitioners, implementation, communication and knowledge mobilisation experts, a range of educators (schools, colleges and higher education), media specialists, and representatives from professional and community organisations, dementia-specific organisations and from diverse communities (minority ethnic groups, LGBTQ+). In addition to older people, younger people should also be included to ensure issues that may be more relevant to younger age groups are considered and incorporated.

A key focus of the COP should be supporting people to identify and create their own housing solutions, supporting coordination between local authorities and the different policy sectors across housing and health, responding to emerging evidence and changing individual and community needs over time. Given the evidence that behaviour change (including attitudes, knowledge and understanding) needs to move beyond the individual (whether patient, carer, practitioner or policy maker), to the wider community and society the COP should be informed by an evidence-based approach to behaviour change, such as the PEN-3, a model that centralizes culture in the study of health beliefs, behaviours, and health outcomes. It also places culture at the core of the development, implementation, and evaluation of successful public health interventions. The model consists of three primary domains: (i) Cultural Identity, (ii) Relationships and Expectations, and (iii) Cultural Empowerment. Each domain includes three factors that form the acronym PEN; Person, Extended Family, Neighbourhood.

The first objective of the COP should be to review the evidence in Greater Manchester on housing for those living with dementia (including this report), identify key interventions/targets, and map an implementation and evaluation strategy both within local authorities and across Greater Manchester. Such mapping should consist of five steps within an agreed timeframe:

- Conduct an implementation needs assessment and identify adopters and implementers
- State adoption and implementation outcomes and performance objectives, identify determinants, and create matrices of change objectives
- Choose theoretical methods (mechanisms of change) and select or design implementation strategies
- Produce implementation protocols and materials
- Evaluate implementation outcomes

The tasks are iterative with the COP returning to previous steps throughout this process to ensure all adopters and implementers, outcomes, determinants, and objectives are addressed.
### Recommendation #7

**Evidence based policy and practice**

Underpinning this recommendation is the fundamental question to us all of how we, as a society, live well with dementia together.

Further research is needed on a number of fronts including (but not limited to):

- Improving public awareness and understanding of dementia and the implications for housing and communities.
- Understanding the changing needs of people living with dementia, taking into account the diversity of the population, and how different housing options do or do not meet such needs over time.
- The relationship between good end of life care and good housing.
- How best to support communities of practice that are evidence-based to remain responsive over time.
- How best to develop and support a logical, systems approach to housing for this population.
- Understanding the importance of ageing in place and neighbourhoods for those living with dementia, how this intersects with fluctuations in the condition, identity, and the implications for housing.

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### Summary of Recommendations

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<thead>
<tr>
<th>Housing with Care</th>
<th>Planning and Development</th>
<th>Building a Community of Practice</th>
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<td><strong>Recommendation 1: Accessible Guidance and Information</strong>&lt;br&gt;We provide independent housing information and advice in a diverse range of accessible formats, for people who receive a diagnosis of dementia, together with their families and carers.</td>
<td><strong>Recommendation 2: Integrated Pathways</strong>&lt;br&gt;Through our adult social care teams and VCSE partners, we ensure housing is integral at every stage of the dementia care pathway. We ensure our support offer includes opportunities to explore housing options as well as financial and legal planning.</td>
<td><strong>Recommendation 6: Knowledge mobilisation and implementation</strong>&lt;br&gt;To enhance and sustain change, we recommend the establishment of a community of practice and learning and information networks among practitioners to receive and share best practice on housing and dementia, informed by engagement and involvement of those living with dementia and their carers. The community of practice will take forward the recommendations in a 5-stage Implementation Plan, with clear targets and evaluation strategies.</td>
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<td><strong>Recommendation 3: Planning Ahead</strong>&lt;br&gt;Through our planning departments, identify clear requirements for housing to meet the diverse needs of people living with dementia, including those from minority communities. We allocate ‘suitable sites’ (e.g. in town centres), identified in conjunction with local housing and care providers specifically for age-friendly housing.</td>
<td><strong>Recommendation 4: Market-Shaping</strong>&lt;br&gt;Through our housing strategy teams, we recognise the growing demand for age-friendly and dementia-ready social and private rented housing for those currently living with dementia in unsuitable homes, including those among ethnic minorities and LGBT communities.</td>
<td><strong>Recommendation 7: Evidence based policy and practice</strong>&lt;br&gt;There is much that remains unknown about the relationship between housing and living well with dementia. To ensure cutting edge practice that is evidence based, further research is needed.</td>
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</table>
The aspiration is to offer commissioners in Greater Manchester a framework to direct and shape services and ensure opportunities to live well with dementia in Greater Manchester.

Part 4. Next Steps

This report has explored pervasive issues relating to health inequalities generally and how housing intersects and exacerbates these for those living with dementia and their carers. It has brought together the views of people and communities from across Greater Manchester and beyond: people with lived experience, academics, public servants, councillors and GPs, developers and nurses, and many more. The thread that unites all of these discussions was the desire to improve the lives of people living with dementia and their carers through housing, particularly in response to damage wrought by the coronavirus pandemic. The signing of a Tripartite Agreement between GMCA, GMHSCP and GMHP in March 2021 is a milestone in this respect, as is the Framework* for Creating Age-Friendly Homes in GM launched in November 2021. This report is another expression of that ambition, framed against a broad backdrop of views we have sought to bring together from across Greater Manchester.

The seven recommendations offer the basis of a three-year Implementation Plan 2022-2025, to be developed through a series of workshops, aimed at developing collaborative conversations that emphasise an assets-based approach, and taking advantage of the developing Integrated Care Systems (ICS) framework in GM.

The plan will be informed by this report and use Recommendation 6 as its foundation, i.e.:

- Conduct an implementation needs assessment and identify adopters and implementers
- State adoption and implementation outcomes and performance objectives, identify determinants, and create matrices of change objectives
- Choose theoretical methods (mechanisms of change) and select or design implementation strategies
- Produce implementation protocols and materials
- Evaluate implementation outcomes
- The tasks are iterative with the COP returning to previous steps throughout this process to ensure all adopters and implementers, outcomes, determinants, and objectives are addressed.

The aspiration is to offer commissioners in Greater Manchester a framework to direct and shape services and ensure opportunities to live well with dementia in Greater Manchester through a clear and consistent offer across policy and practice across the city-region, regardless of geography, culture or individual identities.

References


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