



BEYOND THE FRONT DOOR: What 'home' means to people with dementia and their carers

EXECUTIVE SUMMARY

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Life Story Network CIC

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Acknowledgments

Thank you to: residents of Barkla Fields, Cherry Tree Court, Mazenod Court, Morley Court and Quarry Court; Liverpool African Elders; Liverpool Somali Elders; Liverpool SURF group; Everton in the Community Older People's Group; Irish Community Care; Julie and Phil Dickinson; Dave and Eileen Gilbert; David and Moira McGloughlin; LGBT Foundation; British Association of Occupational Therapists Housing Special Interest Group (north west); Jill Pendleton and Emma Stafford; Emma Bragger; Aimee Attrill and Sharon Lewis; Isobel Godwin; Halton Housing; Liverpool Housing Trust; Liverpool Mutual Homes; Margaret Flynn; Bryony Redwood-Turner

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Beyond the Front Door

‘As people become aware of the finitude of their life, they do not ask for much. They do not seek riches. They do not seek more power. They ask only to be permitted, insofar as possible, to keep shaping the story of their life in the world - to make choices and sustain connections to others according to their own priorities.’ (Gawande, 2014)

Introduction

The project is designed to contribute to existing practice across sectors in post-diagnostic support and, in particular, builds on the work of the Life Story Network in its ‘Your Community Matters’ programme (2013) which acknowledged the value of social housing associations in supporting people living with dementia in their communities. It is widely recognised that social housing associations have come late to the table in getting to grips with the current and future challenges of dementia and what this will pose for them as a sector.

The DH and LSN Project

The LSN was commissioned by the DH, as part of their programme to improve post-diagnostic support, to find out what ‘home’ means to older people and people with memory loss in relation to their sense of identity. This is particularly pertinent to the many people with dementia who find themselves stuck in hospital waiting for social care or other resources to be available. Often these will be residential care places and – if the individual was admitted in a crisis – they may never see their home again.

‘Home’ has different meanings, for example, for people who have been harmed, for immigrants, for people in low income housing, specialist housing and home owners, with implications for their expectations and emotional attachments. These may differ according to age and whether we have raised families in our homes. All this confirms the unique understanding of ‘home’ to each of us. It is only when we have acquired a sense of the deep significance of ‘home’ to individuals that we can negotiate how best to support them, and where, at a time of potential change.

It is known that people with memory loss function best in a familiar environment, although there will be exceptions, for example people who have experienced abuse or significant trauma at home.

Aims and objectives of the project

The aim of this project is to:

- Explore issues relating to the concept of ‘home’ to better understand their importance in relation to the sense of identity and wellbeing for people living with dementia, in order to improve post-diagnostic and multi-agency support.

The objectives of this project are to:

- Gain greater insight into the understanding of ‘home’ for people living with dementia
- Develop awareness amongst professionals, particularly housing support staff, charged with supporting people living with dementia to continue to live at home
- Enable better transitions to take place if someone living with dementia has to move
- Contribute to the implementation of compassionate relationship-centered care and support
- Develop a set of products that support staff in working with people affected by dementia across the range of agencies (housing, NHS Trusts, NHS and local authority commissioners), with responsibility for both commissioning and providing meaningful post diagnostic care and support.

What we did

Our initial phase focused on a series of semi-structured interviews and guided conversations with individuals and groups. We wanted to explore matters of importance to older people, people with dementia and their family carers and to develop an understanding of the complexities of the links between ‘home’, ‘identity’, ‘personhood’ and ‘well-being’. Topics were introduced to enable participants to respond in relation to their current, past and future situations, asking them to consider specifically the effects of moving home.

The project was located in the Liverpool City Region and the housing providers who accepted the invitation and contributed additional funding to the project comprised:

Liverpool Mutual Homes
Liverpool Housing Trust
Halton Housing Trust

We held discussions with:

- six groups of residents in sheltered or extra care schemes in the three boroughs.
- Liverpool Somali Association
- Irish Community Care
- African Elders
- members of the Liverpool Service Users Reference Forum (SURF) and

- a group of older people who meet regularly at Everton Football Club.

We sent the interview template to some people with dementia and carers who had expressed an interest in the project but were unable to attend a meeting.

In total, we met with 60 older people, people with dementia and carers.

Having collated their views, we met with housing providers and other professionals to discuss the findings and elicit their views on how they could improve their service delivery in the light of these. We included in our meetings an opportunity for all participants to reflect on what ‘home’ meant to them to enable them to gain a better understanding of the importance of the concept when working directly with people with dementia and family carers at the point of transition.

We focused on the groups of professionals below with key roles in post diagnostic care and support:

- **Housing staff** - to understand better their awareness of the issues related to people living with dementia facing the prospect of a physical move to a new home.
- **Hospital discharge teams** – to ensure that people living with dementia and their families have their needs and wishes recognised and respected and work with other partners in enabling people to be discharged in a safe and appropriate manner.
- **Social Care Assessors / Care Managers /Occupational Therapists (OTs)** – who are instrumental in assessing the needs of people living with dementia and their family carers, taking account of what really matters to them in terms of their ongoing level of independence, health and wellbeing.
- **Commissioners (NHS and Local Authority)** - who play a pivotal role in ensuring that there is a range of appropriate post diagnostic care and support, including the availability of housing options available within the local community to meet the needs of their local population.

The challenges in engaging with people from seldom heard groups such as LGBT people and older people without children were principally those of time and preparation. That is, we were reluctant to embark on what may have been perceived as ‘hit and run’ fact finding. We are aware that these groups of people have particular needs and drew on preparatory contacts (which we continue to build on) and research findings to ensure their concerns were reflected in our findings.

What we found

People readily and deeply engaged with the opportunity to think about home and the part that it plays in their sense of self. It was clear that home is a place of deep meaning and that our bonds to our homes are unique. Our conversations at times felt quite therapeutic as people were given the chance to talk about matters of significance to them. The realisation by professionals that they held similar views to those of older people had a powerful effect and helped them understand the importance of exploring these matters specifically when talking about moving house, being discharged from hospital or going into a care home.

The following themes emerged from our interviews:

1. Connectedness – our relatives, friends, neighbours and memories matter to all of us

‘My home is part of my past life, formative periods of my life... sense of presence of others... being part of local community’ (Moira and David McGloughlin)

The prospect of having to move away was described by many as a deeply distressing proposition.

Many people referred to home as a place of family - a place where they had brought up their children; *‘my first home when I got married’*, a place where family could come to. *‘Home is where my family are’*, said one woman from Irish Community Care; *‘Home is where you live with your family’*, concurred a Somali Elder, adding that *‘Liverpool 8 is where our friends are, we know everyone, it makes us feel good’*.

At the housing schemes people made clear how important relationships contributed to feeling *‘at home’*. These relationships provided them with friendship, comfort, conversation, company, security and the sense and maintenance of *‘connectedness’*.

The family connection with home is strong for many people as an Irish man noted: *‘home is where my family are’*. Eileen told us that *‘home is where Dave is’*. For one professional, relationships were far more important than the physical place: *‘I’m a free spirit – I can settle anywhere’*.

2. We are active in personalising and creating home

Our emotional attachment to home is complex and is linked with the building, locality, furniture and significant possessions. The personal nature of home was described as both the place where ‘you put your stamp on it’ and ‘home is what makes a person’.

“We used to have a shared living house, specifically for the Irish Community. Some people, who lived there for many years and thought that it would be their home for life – they painted it, planted the garden and painted the bench in the Irish Flag colours. Then the funding for supported living was reduced and we lost the house. The people who lived there were just split up as their particular health needs were different and were changing. Still they had many happy memories from there. The garden bench has been moved, but people still come and visit and sit on it!”

(ICC Care Worker reporting on a ‘supported living house’ specifically for Irish people)

3. Control over decisions about how and where we live is fundamental to our sense of home

One group described how not being able to make your own decisions made a place ‘unhomely’. They felt that living in your own home but with someone else’s rules, can feel belittling.

Some people raised concerns about how decisions were made about what possessions should move with the person. One person described how her children made decisions about what moved with her.

In our own homes, negotiations over space, territory, privacy and control take place. Typically, there are levels of negotiated autonomy. Although the use of space may not be explicitly discussed, sharing space is an unavoidable feature of living with others. At Barkla Fields, the importance of having one’s own private space away from others suggested a clear distinction between people’s own flats and the communal space: ‘My flat is my home, not here’ said Dave, referring to the communal lounge.

“Toxteth was my home, I was 40 years there. I had a difficult life – poverty, hardship – my husband was drinking and gambling, but it wasn’t his fault. In those days, the only place to go and meet up with other Irish people was the pub. I am still an independent woman, my family [son and daughter] wanted to sling everything out from my house – the settee was from my son, who died. My dressing table was mine, I paid for it. I had to scrimp and save for it. I just don’t feel myself anymore! I have to please them, [referring to her son and daughter]. These days they just put those [older people] away - that is what they now do with older people. I moved into supported living, but very disappointed with it! I loved my little home in Toxteth. I now feel like an awkward outsider in it [supported living flat]. Moving into this place where there is such extravagance, the lights are on everywhere all of the time! I had to scrimp and save to get everything I had. I can’t be doing with it, it’s just not me! I don’t see anyone from one day to another and then it is only by chance that I might meet someone on the stairs.”

A 92 yrs. old widow, recently moved into supported living.

This story touches on several other issues: the sense that older people’s histories are unknown or unwittingly ignored and the loneliness that can ensue from a move that has overlooked a person’s feelings and wishes seriously.

4. The meaning of locality; the importance of familiarity; the sense of connection to people and places are critical

‘a house is where you sleep; a home is where people are’

People were clear that home is a place where meaningful activity takes place - ‘*You stop at a hotel, but you live at home*’. Developing new routines and activities has given some people a new lease of life. One participant related her feeling that the housing scheme had enabled her to incorporate her previous life into her current one and this gave her place a sense of homeliness. Retaining routines that have been part of lives for years remain important anchors.

Relationships with support staff play a significant part in the sense of homeliness. Staff attitudes and cultures were implicitly referred to. Acts of kindness were consistently noted; they preferred staff who supported them to do things themselves rather than staff who ‘did for’. Active involvement with others rather than passive was the implication. The term ‘customers’ – used by housing staff to refer to people living

in their properties – was felt to be insulting by some and there was a clear view that you don't call someone living in their own home a 'customer'!

5. Cultural roots - home can be more than one place; new places can be adopted to feel like home; home can be where we are born

The location of home is complex. Some African Elders and Irish Travellers referred to their places of birth rather than where they now live; others said that home could be in more than one place. Thus, home is a physical place and an experience of self in relation to others and although the perception of home is influenced by ethnic identity, uniqueness prevails:

'Somalia is where we were born so it has special status in our memories and hearts'

'I'll go back to Somalia when my family have grown up'

And

'I've been here 60 years, this is my home'

Cultural links and connections were understandably a strong link for many participants. For some people living in their cultural community was important whereas for others, integration also meant that they could call a place home.

I had moved into a flat – settled and homely. A nice atmosphere. I was then moved into a new flat – there was no atmosphere, the walls were like cardboard, I was just stuck there on my own and I feel very trapped. I want to have a bit of company – want to have a cosy home. My dad was a traveller and continued to be in that community when he moved – he would never settle in a flat or a house. I have been a loner all my life and whilst I have met a couple of women from the travelling community, but didn't stay with them. There are times that I lay on my bed and would love to be back there [travelling around] again, but now at age 63 my age is against me!"

A touching story was related to us by a worker at Irish Community Care that highlighted the sense of identity with place of birth:

"My uncle moved to New Zealand and when he died he wanted to have his ashes brought back 'home' to his mum and dad's grave. He also wanted his inscription to read: "I am a son of a son of Ireland."

Thus, the endurance of belonging to community may extend beyond the lifespan.

6. Cultural expectations and needs - the need for recognition of 'how we do things'

The home is associated with status, for example, for the head of the family. This was explained by Somali Elders – home is a place where *'people listen to us and ask our advice'*. *'Once you are out of the house, you are just anybody'*. For others, it is a place where family and friends gather for significant events such as birthdays, weddings and funerals.

Some people described situations where established tenants had been unwelcoming and this had made their transition difficult. Others told us of problems with neighbours and how having felt unsafe in neighbourhoods with changing demographics and developments became the impetus for their relocation.

7. Emotional attachment to places and belongings is comforting and familiar

During a conversation about the importance of objects and keeping memories alive, people identified items that held memories and were part of home for them. These included a golf set, train tapes, photos; a bike; dishes; cutlery, bed, wardrobe, table, chairs, a dresser; a Cuckoo clock bought for mother, now deceased; a Welsh dresser, chairs, photos. For the Somali elders, camel bells were the treasured objects that they brought with them to their new country as reminders of their homeland.

One woman described how, many years earlier, she had set her heart on a table and chairs but couldn't afford them. Her husband had secretly put money down each week to buy them for her. She said that she wept at the thought of letting this furniture go when it came to moving into Extra Care housing. Her daughter eventually agreed to have them at her house, so now when she visits her daughter she can sit in one of her chairs at her table.

8. We value the safety and security of our homes but these may be compromised by external forces and events

The concept of safety and security was high on people's agenda. Home is *'somewhere safe - the safest place'*. One professional talked about her home as *'sanctuary'*. Several factors were cited as contributing to this sense of safety and security: having sources of help, familiarity, neighbours, relationships, family, building, neighbourhood, a place of refuge. People talked about feeling safe from harm, fear, danger, emotional pain, loss of control and risks. These points were also made in relation to living in Sheltered or Extra Care housing.

Whilst we heard positive stories of moves for people, some made it clear that they had moved because relationships had broken down, reminding us that home can also be a place of fear and insecurity. One person described how moving to Barkla Fields [sheltered housing scheme] had enabled her to build new friendships, develop

a new sense of community and have a greater sense of home. One woman recalled how she had a fall and within five minutes people had rallied round to help her up; this contrasted with a five hour wait in her previous home.

For some people, there was recognition that old age can bring with it frailty, a loss of energy, ill-health and other losses that have the potential to transform a comfortable and safe home into an unsafe place of fear, worry and vulnerability. Such feelings were illustrated with accounts of social isolation, loneliness, reduced activity and poor health. People talked about how they had to face up to these changes and how their feelings were not always recognised sufficiently by others.

9. Information about available housing options and knowing where to go for help are essential

In some people's eyes, there is a stigma about moving into housing schemes. There were comments about how people were not clear about the difference between housing and care homes, and one woman said that she had been very reluctant to move from her home until she had actually seen the complex and realised that she was not being asked to move into a care home. Her view, acknowledged by others, was *'that's for older people, it's not like being at home'*.

An issue raised by several people was that of being uncertain about what housing options were available, if they were to move. In talking with housing providers, there was variability about the extent of the information that they provided as well as the quality of support provided to people considering a move from their homes. Increasingly, the requirement for making a housing application is on-line, with little or no support available to do this.

Housing staff described how they sought to make sure that information about the needs of residents was given to hospital staff, often going to the trouble of providing a summary to accompany an individual in the ambulance, and advocating on residents' behalf. However, they see little evidence that such information is used in planning for a resident's return. It would appear that hospital staff assume that sheltered housing or extra care housing provide nursing care, so people may be discharged home (sometimes without the scheme manager being notified) without additional support: *'It's a losing battle – we do our best but ...'*

For tenants living in general housing, we learned that each housing provider determines its own policy in relation to the level of funding they will provide to adapt properties in relation to a Disabled Facilities Grant. Some RSLs have a blanket policy of not adapting properties at all (other than minor adaptations such as grab rails) due to concerns about the ability to re-let in the future; their offer is to rehouse someone to more suitable accommodation. It is hard to identify how such a policy accords with the requirement to make reasonable adjustments for people with protected characteristics.

Professionals responsible for delivering post-diagnostic support confirmed that they do not currently include specific opportunities to explore housing matters and whether current arrangements will remain suitable as people's dementia progresses. Julie and Phil Dickinson's story illustrates the importance of finding an architect who

understands dementia; they were fortunate, but others may not know where to look for one. The SURF group advised that such discussions about housing would be helpful and, as a result, invited a housing representative to come to a future meeting to describe the options available.

Implications

An aim of this project is to develop awareness amongst professionals about the issues that people have told us are important to their sense of identity in relation to 'home'. A common thread is the need for staff to understand and recognize legal requirements relating to disability and discrimination and for people with dementia and their carers to be more informed about their rights and entitlements, so that they can advocate on their own and others' behalf. The implications for specific groups include:

People with dementia

- valued the opportunity to discuss the meaning of 'home' and its importance in formulating their sense of self and what matters to them
- want opportunities to articulate their needs and wishes to professionals who may have other plans for them
- our project spurred some people into realizing that such considerations are important and could be helpful in terms of making sense of their circumstances for their own benefit and also help to prepare them should their circumstances change. They
- are expected to defer to clinical advice that admission to residential care is necessary, this may occur without reference to how they were managing prior to hospital admission; most people do not elect to go into a care home.
- the earlier you start planning, the easier the process of moving
- would be encouraged to think about their housing needs whilst they are still able to make positive choices, if there was dedicated time within a post-diagnostic support programme.
- do not know where to find information, although lots of it exists

Carers

- needs and wishes of carers may differ from those of the people they care for
- 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.
- would benefit from such discussions within a post-diagnostic support programme,
- carer assessments should include consideration of housing need and the significance of 'home' for the carer.

- major implications for the carer in thinking about whether to move home which must be considered alongside those for the person with dementia; many carers draw support from neighbours and friends, who may be vital lifelines in terms of emotional support, social contact and informal respite arrangements.
- Will probably be responsible for organising a move, even if the decision has been arrived at together.

Hospital discharge teams

- the significance of 'home' for patients may not be known to staff
- opportunities should be created for people to discuss what matters to them in relation to home – both the place and the people – so that appropriate help and advice can be offered
- a rights-based approach should be reflected in assessing and managing risks. Hierarchies within hospital settings persist and medical opinions are difficult to challenge.
- Best Interest Decisions should take account of as much information as possible about the individual's known wishes and aspirations and living circumstances prior to hospital admission, not just during the crisis period that may have led up to it. Using a rights-based approach should enable a balanced appraisal of the risks in returning home and being admitted to residential care for example. This project underlines the need for negotiated support planning and decision making.
- housing staff should be included in discharge planning as equal partners so they can share valuable information about individuals and how they were managing at home
- assumptions may be made about what sheltered or extra care housing provide without checking these out with housing staff, so people may be discharged inappropriately
- discharge teams should be up to date in terms of: local housing and support options; access to these options; changes in benefits linked to housing; and eligibility criteria for Disabled Facilities Grants. Building professional networks with local housing providers will bring benefits not only in terms of knowledge of resources but also in mutual trust and confidence when planning for and with individuals.

Social care assessors

- should introduce the topic of housing needs at the earliest opportunity, exploring all possible options
- should have an understanding of the significance of home, place and associated relationships
- occupational therapists are key, given their attention to maintaining activities of daily living and their expertise in assessing how well people manage in their physical environments, but may be reluctant to commit to

major adaptations in an individual's home given the progressive nature of dementia

- need to be mindful of the Mental Capacity Act when assisting people to assign up for tenancies and should familiarise themselves with the expectations and requirements of housing providers

Housing staff

- participants valued the opportunity to think about the information they have about their provision and the degree of contact and advice they give at critical points: that is, application; offer; moving in/induction; and follow up/review
- some people do not have families to support them through the process, so housing staff may need to assume a more active role
- some families may disguise or underplay difficulties of the cared-for person for fear of jeopardising the offer
- some difficulties may be masked in the person with dementia by their care-giving spouse or partner and may only become apparent when the care-giver has died
- clear information and pro-active dialogue at the point of application would provide a compelling benchmark by which the discussions at the offer stage could be measured, to help reduce inappropriate re-locations
- a 'settling in pack' for new residents to ease the transition into schemes, especially if most residents have lived there a long time; schemes without a warden may be slow to identify emergent problems
- bespoke training about dementia and its impact on the person diagnosed and their carer would equip staff with tools and techniques to work directly with people with dementia, beyond the basic awareness raising that Dementia Friends offers
- housing leaders have a responsibility to make sure that housing developments incorporate dementia-inclusive features, such as lighting, signage and bathroom fittings, at the design stage. There are plenty of materials available to assist, such as those produced by Stirling University Dementia Services Development Centre and the Kings Fund.
- Although there is representation on the Health and Well-being Boards, there was general agreement that joint working at operational level was lacking. Housing staff did not believe that they had a '*seat at the table*' so were not regarded as equal professionals by their health and social care colleagues.

Commissioners

- there are significant gaps in service provision, with a continued reliance on what already exists rather than finding creative solutions.
- investment in services to enable people to return home with intensive support, rather than deteriorating as a result of prolonged hospital stays, would elicit more realistic assessments of people's abilities and strengths

- in their home environments, rather than reliance on assessments in the false setting of acute hospitals.
- participants in our multi-agency workshop suggested that we should be '*commissioning for home*', to highlight the need to address the importance of 'home' and what it means to people. This would crystallise what person centred care means and how it can be provided more effectively, for example home based respite care rather than a choice limited to care homes. It would also support discussions about home and what it means at a much earlier stage so that people could plan their transitions ahead and reduce the likelihood of crises occurring.
 - need to test out their assumptions about what is being provided. For example: what are the components of post-diagnostic support? Are people offered a structured programme that includes the opportunity to explore housing options, as well as financial planning and legal matters? What level of individual support do people actually receive in residential care?
 - The Care Act has given local authorities a duty to shape the care market to meet the needs of their local populations. They should include groups from all communities in their commissioning strategies: black and ethnic minorities, LGBT, people without children, people with learning disabilities and people with young onset dementia. Continuing to commission solely on the basis of a deficit model – what people can't do – rather than one that also supports active citizenship, builds on strengths and recognises the value of social relationships, is no longer viable. Housing has a key role to play in this regard both strategically and as part of service provision to meet individual needs.

Conclusions

When older people, people with dementia, family carers and professionals had the opportunity to think about what 'home' means, this was highly valued. It illuminated matters that they had not thought about explicitly before. It highlighted the responsibility of professionals to create similar opportunities as they assess people's needs, particularly at times of crisis.

Multi-disciplinary working is crucial in ensuring best outcomes. Where people are living in social housing, staff involvement can ease transitions. Unfortunately, many housing providers have withdrawn managers from sheltered schemes as a result of cuts in Supporting People funding and have replaced them with neighbourhood or area co-ordinators/managers whose remit is far wider. This project confirms that where they still exist, they play a significant role in facilitating transitions for new residents, guiding people through the application and acceptance processes and brokering their introduction to existing residents.

Since dementia is a process that undermines the '*ability to preserve a sense of themselves as a unique and valuable being*' (Cheston and Bender, 2003) supporting people to plan ahead in advance of significant cognitive challenges developing may enable consideration of housing options. This may include adaptations to their

existing property, moving to more accessible accommodation or re-locating to be nearer family members.

The project shows how the maintenance of memories, cultural activities and values and familiar relationships play a significant role in self-identity and consequent well-being. These insights are relevant to professional practice which aims to achieve positive outcomes both for people and economic benefits for health and social care.

Finally, our findings confirm the crucial role that housing plays in supporting people with dementia and carers. The sector should be included as an equal partner in planning and designing services for older people as well as a significant player in service provision.

‘Social care, health and housing are three legs of a stool. Underinvest in one, and the stool can only wobble on two legs for so long ...’

Watts, (2016)

Key recommendations:

The Life Story Network is proactive in sharing valued and insightful practice and we propose to share this report across our networks. It is our view that the following recommendations will be useful in tilling the ground for productive discussion and developments.

1. This report should be distributed within NHS England, Public Health England, ADASS, the LGA, Dementia and Housing Working Group, the Carers Trust and other key voluntary sector organisations to highlight the importance of ‘home’ and its relationship with identity and well-being, in particular for older people, people with dementia and their carers
2. After a diagnosis of dementia, support programmes should include opportunities to consider people’s homes, their housing needs and planning for the future, alongside financial planning, making a will and having a Lasting Power of Attorney for example
3. NHS and social care assessors should include discussions about what home means to individuals to inform their assessments, care and support planning and risk assessments
4. Registered Social Landlords should review the information that they produce about the types of housing they offer and ensure that these are described in straightforward language. They should also set out what potential residents can expect in sheltered housing, extra care housing and group living schemes, for example, and should consider a “Settling-in Pack” for new residents. Their information should ensure that people from particular communities, e.g. LGBT people, those from minority ethnic groups and people without children, feel welcomed and that their needs are of equal importance.

5. Registered Social Landlords should review their processes – in relation to applications for accommodation, making offers, signing tenancies, induction into properties and reviews of tenancies – to ensure that all options are explored and explained fully. This should smooth transitions and mitigate the distress associated with having to move, minimise the risk of moving into unsuitable accommodation and identify emerging problems as early as possible
6. Health and social care commissioners should be encouraged to start '*commissioning for home.*' This should make explicit the importance of home in relation to our identities and well-being
7. Registered Social Landlords should include in their workforce development plans bespoke training on (i) the impact of dementia on people who have been diagnosed (ii) the impact on their relatives and friends and (iii) the ways in which housing professionals can support people to live well with dementia
8. Registered Social Landlords should be included as equal partners in planning forums for older people, people with dementia and carers
9. NHS bodies, local authorities and Registered Social Landlords should ensure that older people, people with dementia and carers are involved in strategy development and service design, including housing developments
10. Commissioners, NHS Trusts, local authorities, social care providers and Registered Social Landlords should satisfy themselves that the services they are commissioning and providing are compliant with the Equalities Act and the Human Rights Act, particularly in relation to people with dementia. They should make sure that policies in relation to adaptations, for example, do not inadvertently discriminate against people with dementia.



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IMPLICATIONS FOR POLICY AND PRACTICE

Penny Redwood, Ruth Eley and Anna Gaughan

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Introduction

A core commitment of the Prime Minister's Challenge on Dementia 2020 is to enable people living with dementia to be supported to live independently in their own homes for as long as they are comfortable and safe to do so. It is recognised that this will include adaptations to accommodation and exploring housing options as well as social care support to preserve independent living for as long as possible. In the Challenge's Implementation Plan, there is a commitment that the Department of Health (DH) will work closely with the Life Story Network (LSN) to focus on older people and people with dementia who live in social housing, to ensure they are supported to live in their homes for longer with a focus on independent living, avoiding costly crisis care and emergency admission to hospital as well as delaying admission to residential care.

This project recognises the multi-disciplinary input required to enable such outcomes and the role it plays in post-diagnostic support. The project is designed to contribute to existing practice across sectors in post-diagnostic support and, in particular, builds on the work of the Life Story Network in its 'Your Community Matters' programme (2013,) which acknowledged the value of social housing associations in supporting people living with dementia in their communities. It is widely recognised that social housing associations have come late to the table in getting to grips with the current and future challenges of dementia and what this will pose for them as a sector.

The DH and LSN Project

The emphasis on maintaining older people at home for as long as possible, retaining and enabling skills and activities of daily living, is hugely significant. Person-centred care is crucial in respecting older people's individuality and in enabling them to live the lives that they want - making choices and having control over activities and decisions. A big decision that most of us make is where we should live, and how. *'There's no place like home'* is a familiar adage, and if we stop to think about what *'home'* is, we realise that it provides us with far more than shelter.

This project was designed to find out what *'home'* means to older people and people with memory loss in relation to their sense of identity. Armed with this knowledge, the project's aim was to develop resources that would be useful to professionals, as well as older people and their carers, to enable issues of crucial importance to people's sense of identity to be taken into account when a transition from home is being discussed. This is particularly important since too many people with dementia find themselves stuck in

hospital waiting for social care and other resources to be available. Often these will be residential care places and – if the individual was admitted in a crisis – they may never see their home again.

Our premise is that the idea of home is inseparable from our sense of self and our sense of identity. We invest in creating our homes as we want them - financially and emotionally. Our homes are places that we fashion; they become assets, places of collective and personal memories, *'containers of meaning and symbol, as theatrical sets against which dramas of our lives are enacted'* (Heathcote, 2012).

One of the most influential factors in all our lives is the environment in which we live and home provides a major focus in life. *'As people age they become more orientated towards home; it is seen as a refuge and becomes increasingly important as other social roles in later life are relinquished.'* (Bond, 1993)

'Home' has different meanings, for example, for people who have been harmed, for immigrants, for people in low income housing, specialist housing and home owners, with implications for their expectations and emotional attachments. These may differ according to age and whether we have raised families in our homes. All this confirms the unique understanding of 'home' to each of us. It is only when we have acquired a sense of the deep significance of 'home' to individuals that we can negotiate how best to support them, and where, at a time of potential change.

It is known that people with memory loss function best in a familiar environment, although there will be exceptions, for example people who have experienced abuse or significant trauma at home. *'...it is increasingly clear that the environment in which the person with AD (Alzheimer's disease) dwells can exert a potent effect upon his or her cognitive and behavioural abilities'* (Sabat, 2002).

Housing staff may not be equipped with the appropriate information, knowledge and skills to provide the necessary support to a tenant with dementia. Unwittingly, this can have a negative impact on tenants, colleagues and ultimately on the financial viability of social housing associations.

Aims and objectives of this project

The aim of this project is to:

- Explore issues relating to the concept of 'home' to better understand their importance in relation to the sense of identity and wellbeing for people living with dementia, in order to improve post-diagnostic and multi-agency support.

The objectives of this project are to:

- Gain greater insight into the understanding of 'home' for people living with dementia
- Develop awareness amongst professionals, particularly housing support staff, charged with supporting people living with dementia to continue to live at home

- Enable better transitions to take place if someone living with dementia has to move
- Contribute to the implementation of compassionate relationship-centered care and support
- Develop a set of products that support staff in working with people affected by dementia across the range of agencies (housing, NHS Trusts, NHS and local authority commissioners), with responsibility for both commissioning and providing meaningful post diagnostic care and support.

What does the literature tell us about 'home' and identity?

A full literature review can be found in Appendix 1. Concepts pertinent to the sense of identity in relation to 'home' can be summarised as follows:

- place identity; can attachment to a situation or place support or maintain identity? To consider in relation to a sense of belonging; past associations; self-esteem and self-efficacy; is it an enabling environment? What do we call home?
- Locality/community/surroundings; how do these relate to 'home'?
- Connections/social interactions; what part do they play in the idea of 'home' and who we are?
- security/safety/sanctuary/a place of refuge/comfort
- privacy
- stability and permanence
- a place of self-expression/meaning/personal development/healing/restoration
- control and choice/independence
- space

Conceptual Framework

Building on these, we adopted a conceptual framework to help us make sense of what people were telling us.

1. A sense of 'home' is important to people and contributes to a sense of wellbeing

'Housing is an element of someone's identity'

Emma Maier, Group Editor, Inside Housing

The very idea of home is inseparable from our sense of self and our sense of identity. *'Our home is our base, a place that roots us to the earth, to the city or the landscape; it gives us permanence and stability and allows to build a life around it and within it'* (Heathcote, 2012). For people who develop dementia, the preservation of continuity as far as is possible has a positive impact on their quality of life, particularly as they become increasingly dependent on longer term memories.

2. Emotional connection and collaboration are essential characteristics in enabling and maintaining supportive and caring relationships

Being able to make decisions and being in control are important processes that contribute significantly to our well-being. Involving people as equals in their assessment and care and support planning is endorsed in policy and guidance across all sectors.

3. People with dementia should live in their communities as equal citizens with their value recognised and respected

The social model of disability affirms that dementia is not just created by the neurological impairment and its consequent effects, but also by attitudes and environments that are disabling. The unique experience of dementia for people who are diagnosed and for those who care and support them is acknowledged.

4. The person with dementia is at the centre of decision-making and processes related to them and that they should be enabled to be self-determining as far as is possible

'A strengths-based approach to care, support and inclusion says 'let's look first at what people can do with their skills and their resources and what can the people around them do in their relationships and their communities'. People need to be seen as more than just their care needs - they need to be experts and in charge of their own lives'.

Alex Fox, Chief Executive, Shared Lives (SCIE, Care Act, 2014)

We can enable personal control and decision making by recognising people's resources, skills and abilities that they have built up through their lives. These skills continue to have a place in everyday living. This approach is promoted in the Care Act 2014 which underpins practice in health and social care.

Used appropriately, the Mental Capacity Act (MCA) 2005 enables people with memory loss and dementia to be at the centre of decisions about their future care and support, not least in where and how they should live.

5. The promotion of a human rights based approach.

'Dementia support needs to be person-centred and rights-based; it must take into account someone's gender, race, sexuality, ability or socio-economic background. People who have already experienced disadvantage or discrimination may face further inequality if they develop dementia and the support they are offered is generic, instead of being tailored to their particular needs'.

Gill Boston, National Care Forum

Human rights are basic rights that belong to everyone, and people with dementia have the same legal and civil rights as everyone else. Legislation hinges on the Equality Act (2010)

and Human Rights Act (1998), which place duties on public bodies to protect and promote rights.

The Equality Act offers protection for people with dementia to access appropriate person-centred support by recognising dementia in the context of 'protected characteristics'. Organisations are required to make reasonable adjustments to address these characteristics and prevent discrimination.

Of particular relevance to this project is Article 8 of the Human Rights Act, which protects the right to respect for family life, private life, home and correspondence. The concept of private life is interpreted as covering a broad range of issues including the right to develop personal identity, forge friendships and other relationships.

In 2016, dementia was incorporated into the UN Convention on the Rights of Persons with Disabilities so that dementia is now defined as a disability and will be included in the government's review of progress under the Convention, due in 2017. Article 19 of the Convention sets out the right to live independently and be included in the community, including the opportunity to choose their place of residence, where and with whom they live on an equal basis and without obligation to live in a particular living environment.

The importance of taking a rights-based approach is to make sure that the principles of independence, respect, choice and control apply to people with dementia, including those with other impairments such as learning disability and physical disability, as well as to groups of people who may be disregarded in policy planning such as Lesbian Gay Bisexual and Transgender communities, people without children, people from ethnic communities, people who are known as 'hoarders'.

A rights-based approach enables us to recognise the power imbalances that exist between service users and providers and how ageism prevails in the way that decisions are sometimes made.

6. Desired outcomes for people with dementia and their carers

The following outcomes constitute the National Dementia Declaration for England and were developed originally through the Dementia Action Alliance (2011). They have since been revised in 2017 to make them more inclusive of those around the person with dementia, particularly family carers, and reflect better the things that people with dementia and their carers say are important to their quality of life. They remain important principles that accord people with dementia rights and entitlements. They are congruent with a strengths-based approach and person-centred care:

1. We have the right to be recognised as who we are, to make choices about our lives including taking risks, and to contribute to society. Our diagnosis should not define us, nor should we be ashamed of it.
2. We have the right to continue with day-to-day and family life, without discrimination or unfair cost, to be accepted and included in our communities and not live in isolation or loneliness.
3. We have the right to an early and accurate diagnosis, and to receive evidence based, appropriate, compassionate and properly funded care and treatment, from

trained people who understand us and how dementia affects us. This must meet our needs, wherever we live.

4. We have the right to be respected, and recognised as partners in care, provided with education, support, services, and training which enables us to plan and make decisions about the future.
5. We have the right to know about and decide if we want to be involved in research that looks at cause, cure and care for dementia and be supported to take part.

Each statement is underpinned by more detail that incorporates the needs of carers more explicitly than these headlines. Further information and the full Declaration can be found at <https://www.dementiaaction.org.uk/nationaldementiadeclaration>

What we did

Our design was flexible and analysis of the information gained from the interviews and workshops used a grounded theory approach (Glaser and Strauss, 1967). This enabled us to identify and explore matters of importance to older people, people with dementia and their family carers and to develop an understanding of the complexities of the links between 'home', 'identity', 'personhood' and 'well-being'. We were able to discuss the insights we had gained from our conversations with various professional groups.

Prior to meeting, participants were provided with clear, straightforward information about the purpose of the project and the proposed meeting, either by ourselves or by housing staff. Family members and staff where relevant were also given information and the opportunity to discuss any concerns and needs. Consent was also requested for the gathering and use of the information. This was gained through group and one to one explanations to ensure that people understood the implications of their consent.

Our initial phase focused on a series of semi-structured interviews and guided conversations with individuals and groups. Topics were introduced to enable participants to respond in relation to their current, past and future situations, asking them to consider specifically the effects of moving home.

Geographically, the project was located in the Liverpool City Region and we planned to work across Halton, Liverpool and Wirral. Halton Housing Trust, Magenta, Liverpool Housing Trust/Symphony Housing, Plus Dane Housing, Regenda Group, Your Housing and Liverpool Mutual Homes were all invited to participate.

In the end, the housing providers who accepted the invitation and contributed additional funding to the project comprised:

- Liverpool Mutual Homes
- Liverpool Housing Trust
- Halton Housing Trust

We held discussions with six groups of residents in sheltered or extra care schemes in the three boroughs.

We also heard the voices of people from seldom heard groups. We spoke with people from:

- Liverpool Somali Association
- Irish Community Care
- African Elders

We met with members of the Liverpool Service Users Reference Forum (SURF) and sent the interview template to some people with dementia and carers who had expressed an interest in the project but were unable to attend a meeting. We also met with members of a group of older people who meet regularly at Everton Football Club.

The challenges in engaging with people from seldom heard groups such as LGBT people and older people without children were principally those of time and preparation. That is we were reluctant to embark on what may have been perceived as 'hit and run' fact finding. We are aware that these groups of people have particular needs and drew on preparatory contacts (which we continue to build on) and research findings to ensure their concerns were reflected in our findings.

In total, we met with 60 older people, people with dementia and carers. Having collated their views, we met with housing providers and other professionals to discuss the findings and elicit their views on how they could improve their service delivery in the light of these. We included in our meetings an opportunity for all participants to reflect on what 'home' meant to them to enable them to gain a better understanding of the importance of the concept when working directly with people with dementia and family carers at the point of transition.

We focused on the groups of professionals below with key roles in post diagnostic care and support:

- **Housing staff** - to understand better their awareness of the issues related to people living with dementia facing the prospect of a physical move to a new home.
- **Hospital discharge teams** – to ensure that people living with dementia and their families have their needs and wishes recognised and respected and work with other partners in enabling people to be discharged in a safe and appropriate manner.
- **Social Care Assessors / Care Managers /Occupational Therapists (OTs)** – who are instrumental in assessing the needs of people living with dementia and their family carers, taking account of what really matters to them in terms of their ongoing level of independence, health and wellbeing.
- **Commissioners (NHS and Local Authority)** - who play a pivotal role in ensuring that there is a range of appropriate post diagnostic care and support, including the availability of housing options available within the local community to meet the needs of their local population.

Findings and Discussion

The themes that emerged from our interviews are as follows:

- connectedness – our relatives, friends, neighbours and memories matter to all of us
- we are active in personalising and creating home
- control over decisions about how and where we live is fundamental
- the meaning of locality; the importance of familiarity; the sense of connection to people and places are critical
- cultural roots - home can be more than one place; new places can be adopted to feel like home; home can be where we are born
- cultural expectations and needs - the need for recognition of 'how we do things'
- emotional attachment to places and belongings is comforting and familiar
- we value the safety and security of our homes but these may be compromised by external forces and events
- information about available housing options and knowing where to go for help are essential

These themes are explored in relation to the conceptual framework.

1.A sense of 'home' is important to people and contributes to a sense of wellbeing

'My home is part of my past life, formative periods of my life... sense of presence of others... being part of local community'

Moira and David McGloughlin

People readily and deeply engaged with the opportunity to think about home and the part that it plays in their sense of self. It was clear that home is a place of deep meaning and that our bonds to our homes are unique. Our conversations at times felt quite therapeutic as people were given the chance to talk about matters of significance to them. The realisation by professionals that they held similar views to those of older people had a powerful effect and helped them understand the importance of exploring these matters specifically when talking about moving house, being discharged from hospital or going into a care home.

Our emotional attachment to home is complex and is linked with the building, locality, furniture and significant possessions. The personal nature of home was described as both the place where *'you put your stamp on it'* and *'home is what makes a person'*.

Home has a temporal perspective. It is a place of self-expression, of showing the world who we are; it contains objects and memories of deep personal significance. It is part of past life, of the present reality and the future. Since it is a place of formative experiences the prospect of having to move away was described by many as a deeply distressing proposition.

The home is associated with status, for example, for the head of the family. This was explained by Somali Elders – home is a place where *'people listen to us and ask our advice'*. *'Once you are out of the house, you are just anybody'*. For others, it is a place where family and friends gather for significant events such as birthdays, weddings and funerals.



Somali Elders in Liverpool

During a conversation about the importance of objects and keeping memories alive, people identified items that held memories and were part of home for them. These included a golf set, train tapes, photos; a bike; dishes; cutlery, bed, wardrobe, table, chairs, a dresser; a Cuckoo clock bought for mother, now deceased; a Welsh dresser, chairs, photos. For the Somali elders, camel bells were the treasured objects that they brought with them to their new country as reminders of their homeland.

2. Emotional connection and collaboration are essential characteristics in enabling and maintaining supportive and caring relationships

'a house is where you sleep; a home is where people are'

The social nature of home was perhaps the most frequently cited theme. Many people referred to home as a place of family - a place where they had brought up their children; *'my first home when I got married'*, a place where family could come to. *'Home is where*

my family are', said one woman from Irish Community Care; *'Home is where you live with your family'*, concurred a Somali Elder, adding that *'Liverpool 8 is where our friends are, we know everyone, it makes us feel good'*.

At the housing schemes the people that we met had developed important bonds with others and made clear how important relationships contributed to feeling *'at home'*. These relationships provided them with friendship, comfort, conversation, company, security and the sense and maintenance of *'connectedness'*.

Whilst we heard positive stories of moves for people, some made it clear that they had moved because relationships had broken down, reminding us that home can also be a place of fear and insecurity. We heard stories from people where they felt that their neighbours had become *'distant'* or *'absent'*, where they had watched people outside through their windows, but there was no contact. One person described how moving to Barkla Fields [sheltered housing scheme] had enabled her to build new friendships, develop a new sense of community and have a greater sense of home. The women in the group also talked about the reassurance that comes from having people around. One recalled how she had a fall and within five minutes people had rallied round to help her up; this contrasted with a five hour wait in her previous home.

For some people, there was recognition that old age can bring with it frailty, a loss of energy, ill-health and other losses that have the potential to transform a comfortable and safe home into an unsafe place of fear, worry and vulnerability. Such feelings were illustrated with accounts of social isolation, loneliness, reduced activity and poor health. People talked about how they had to face up to these changes and how their feelings were not always recognised sufficiently by others.

Relationships with support staff play a significant part in the sense of homeliness. Staff attitudes and cultures were implicitly referred to. Acts of kindness were consistently noted; they preferred staff who supported them to do things themselves rather than staff who *'did for'*. Active involvement with others rather than passive was the implication. The term *'customers'* – used by housing staff to refer to people living in their properties – was felt to be insulting by some and there was a clear view that you don't call someone living in their own home a *'customer'*!

Case Study: Dave and Eileen Gilbert

Dave and Eileen lived in the same house in South Liverpool for over 50 years. They invested a lot in their rather run down new home, refitting the kitchen, adding a conservatory and building a brick shed at the bottom of the garden. They reared their families in this house and saw them move on to settle in their own homes nearby. They had fabulous neighbours and felt part of a small, cohesive community. Now aged 82, Dave was diagnosed with dementia about four years ago. The couple received helpful post-diagnostic support through Mersey Care NHS Trust, which led in turn to involvement in the Service Users Reference Forum with its associated activities. At about the same time, Eileen was developing mobility problems and beginning to find the stairs in their home a bit of a problem. Their interest only mortgage was drawing to a close and they were unlikely to have enough resources to be able to pay off the capital sum. For all these reasons they were starting to think about moving house.

SURF identified housing as a priority area and were asked by the City Council to assist them in reviewing housing options for people with dementia in the city. As part of this project, Dave and Eileen were members of a group that visited an extra care housing scheme in Knotty Ash in North Liverpool. They thought it was lovely. *'I'd love to move here!'* was a throwaway comment from Eileen, but after discussing the possibility with their family, Dave and Eileen put their names down for an apartment, thinking they would probably have to wait at least a year.

than one place. It seems to be common for people to refer to their parents' home, or their former home where they were brought up, as home as well as their current residence.

All the children have cars and Eileen also drives, so moving to a new neighbourhood was not a major concern for their family; their view was that moving to more manageable accommodation, with care and support on site, was the most important consideration for their parents.

Seven months later Dave and Eileen were offered a flat in the scheme. They were excited about the move, but found it hard to leave the home they had lived in for so many years and their lovely neighbours. They had to change a lot of their furniture because of the smaller size of the apartment. Eileen also got rid of most of the equipment from her catering business, but she kept their crystal ware and china crockery so that they could enjoy using them. They miss their immediate neighbour a lot, but soon realised the advantages of their new accommodation.

They moved in November 2015 and Dave settled into their new home remarkably well – *'that helped a lot'*. He found his way around the apartment quickly and although he sometimes gets a bit confused when they are returning home in the car, telling Eileen that they are going the wrong way, he confirmed that he likes his new home and said it had been *'a good move'*. Care staff call in every morning to check if they need any help and were described by Eileen as *'wonderful'*. Before they moved here, Eileen and Dave would not have considered moving to Knotty Ash but now they are there they like it – *'It's fine'*. They use the restaurant in the scheme occasionally and Eileen has helped sort out the library in the residents' lounge. They are managing to strike a balance between carrying on doing the things they enjoy and are important to them (such as SURF and other dementia-related activities) and forming relationships within a new community.

On Boxing Day, Eileen and Dave hosted a large family gathering, bringing back fond memories of former occasions. It was then that Eileen said to herself *'Yes, now this feels like home'*.



Dave and Eileen Gilbert

Thus home is a physical place and an experience of self in relation to others and although the perception of home is influenced by ethnic identity, uniqueness prevails:

'Somalia is where we were born so it has special status in our memories and hearts'

'I'll go back to Somalia when my family have grown up'

And

'I've been here 60 years, this is my home'

The family connection with home is strong for many people as an Irish man noted: *'home is where my family are'*. Eileen told us that *'home is where Dave is'*. For one professional, relationships were far more important than the physical place: *'I'm a free spirit – I can settle anywhere'*.

Cultural links and connections were understandably a strong link for many participants. For some people living in their cultural community was important whereas for others, integration also meant that they could call a place home.

I had moved into a flat – settled and homely. A nice atmosphere. I was then moved into a new flat – there was no atmosphere, the walls were like cardboard, I was just stuck there on my own and I feel very trapped. I want to have a bit of company – want to have a cosy home. My dad was a traveller and continued to be in that community when he moved – he would never settle in a flat or a house. I have been a loner all my life and whilst I have met a couple of women from the travelling community, but didn't stay with them. There are times that I lay on my bed and would love to be back there [travelling around] again, but now at age 63 my age is against me!"

An individual from the Irish Travellers' Community

A touching story was related to us by a worker at Irish Community Care that highlighted the sense of identity with place of birth:

"My uncle moved to New Zealand and when he died he wanted to have his ashes brought back 'home' to his mum and dad's grave. He also wanted his inscription to read: "I am a son of a son of Ireland."

Thus the endurance of belonging to community may extend beyond the lifespan.

"We used to have a shared living house, specifically for the Irish Community. Some people, who lived there for many years and thought that it would be their home for life – they painted it, planted the garden and painted the bench in the Irish Flag colours. Then the funding for supported living was reduced and we lost the house. The people who lived there were just split up as their particular health needs were different and were changing. Still they had many happy memories from there. The garden bench has been moved, but people still come and visit and sit on it!"

ICC Care Worker reporting on a 'supported living house' specifically for Irish people

This story also shows the effort that people will put into maintaining their sense of cultural identity.

A thread running throughout the interviews was that older people have meaning in their lives. People were clear that home is a place where meaningful activity takes place - 'You stop at a hotel, but you live at home'.

Developing new routines and activities has given some people a new lease of life. All agreed on the need for purposeful activities. One participant related her feeling that the housing scheme had enabled her to incorporate her previous life into her current one and this gave her place a sense of homeliness. Retaining routines that have been part of lives for years remain important anchors.

4. The person with dementia is at the centre of decision-making and processes related to them and they should be enabled to be self-determining as far as is possible

The importance of self-determination and making decisions about how we live is integral to our sense of home. For example, one group described how not being able to make your own decisions made a place 'unhomely'. They felt that living in your own home but with someone else's rules, can feel belittling.

Some people raised concerns about how decisions were made about what possessions should move with the person. Attachments to objects which are associated with people and memories are enduring. One person described how her children made decisions about what moved with her. Another woman described how, many years earlier, she had set her heart on a table and chairs but couldn't afford them. Her husband had secretly put money down each week to buy them for her. She said that she wept at the thought of letting this furniture go when it came to moving into Extra Care housing. Her daughter eventually agreed to have them at her house, so now when she visits her daughter she can sit in one of her chairs at her table.

“Toxteth was my home, I was 40 years there. I had a difficult life – poverty, hardship – my husband was drinking and gambling, but it wasn’t his fault. In those days, the only place to go and meet up with other Irish people was the pub. I am still an independent woman, my family [son and daughter] wanted to sling everything out from my house – the settee was from my son, who died. My dressing table was mine, I paid for it. I had to scrimp and save for it. I just don’t feel myself anymore! I have to please them, [referring to her son and daughter]. These days they just put those [older people] away - that is what they now do with older people. I moved into supported living, but very disappointed with it! I loved my little home in Toxteth. I now feel like an awkward outsider in it [supported living flat]. Moving into this place where there is such extravagance, the lights are on everywhere all of the time! I had to scrimp and save to get everything I had. I can’t be doing with it, it’s just not me! I don’t see anyone from one day to another and then it is only by chance that I might meet someone on the stairs.”

A 92 yrs. old widow, recently moved into supported living.

This story touches on several other issues: the sense that older people’s histories are unknown or unwittingly ignored and the loneliness that can ensue from a move that has overlooked a person’s feelings and wishes seriously.

Housing staff described how they sought to make sure that information about the needs of residents was given to hospital staff, often going to the trouble of providing a summary to accompany an individual in the ambulance, and advocating on residents’ behalf. However, they see little evidence that such information is used in planning for a resident’s return. It would appear that hospital staff assume that sheltered housing or extra care housing provide nursing care, so people may be discharged home (sometimes without the scheme manager being notified) without additional support: *‘It’s a losing battle – we do our best but ...’*

For tenants living in general housing, we learned that each housing provider determines its own policy in relation to the level of funding they will provide to adapt properties in relation to a Disabled Facilities Grant. Some RSLs have a blanket policy of not adapting properties at all (other than minor adaptations such as grab rails) due to concerns about the ability to re-let in the future; their offer is to rehouse someone to more suitable accommodation. It is hard to identify how such a policy accords with the requirement to make reasonable adjustments for people with protected characteristics.

Case Study: Julie and Phil Dickinson

Phil’s father has dementia and now lives in a care home, having previously lived in a flat. Julie and Phil therefore recognised some signs when Phil started having some difficulties when he about 53. He had a few falls and some memory lapses; they realised *‘something was not quite right’*. He was referred to an Ear, Nose and Throat specialist to exclude physical problems, but Julie had a gut feeling that was not the issue. It took a while as they had to wait for various therapy assessments. They did find a problem in one ear but they reassured Phil that it should get better, which it didn’t. He was referred to the Walton neurology unit where he underwent detailed tests with the psychologist; again, all this took a long time. He was discharged from the ENT clinic. Phil finally got a one paragraph letter in July 2013 informing him he had frontal lobe dementia, with no information about follow up or information about where to get further help or advice. They waited patiently, expecting to hear more, but nothing happened. Fortunately, Julie is a friend of the local Alzheimers Society service manager and having told her about Phil’s diagnosis, was delighted when she followed it up on their behalf. The service manager was appalled, particularly as they have a dementia support worker based in the Walton clinic.

An architect friend of theirs drew them a plan which he adapted to what Julie and Phil needed; the house needed to be able to accommodate a downstairs bed space for the future. They also included a breakfast bar in the kitchen as Phil finds this easier than sitting at a table. They got three quotes but decided on a builder who is a friend of their neighbour and who also lives local. Everyone involved was excellent. Phil said he is very pleased with the result. He really loves his new room and can sit comfortably very near to the wet room, so he does not need to worry about getting to the toilet.

The house still feels like home after all the adaptations. They still have some further work to be completed to create a patio and ramped area at the back so Phil can get to the car easily should his mobility deteriorate. The front room is really sunny and Phil likes to sit in the window to watch what is going on. People wave to him as they go by. The neighbours are lovely and are the first call on his new Lifeline alarm. Phil has his things around him wherever he chooses to sit – he is a whizz at fiendish Sudoku!

They think it would be beneficial to include discussions about home in post-diagnostic support. People need to think ahead when they get a diagnosis. Julie and Phil were fortunate in being able to afford to have their house adapted, but if you can't and need social services help through a Disabled Facilities Grant, or if you live in rented accommodation, moving house can take quite a long time.



5. A Human Rights approach

In our own homes, negotiations over space, territory, privacy and control take place. Typically, there are levels of negotiated autonomy. Although the use of space may not be explicitly discussed, sharing space is an unavoidable feature of living with others. At Barkla Fields, the importance of having one's own private space away from others suggested a clear distinction between people's own flats and the communal space: '*My flat is my home, not here*' said Dave, referring to the communal lounge.

The concept of safety and security was high on people's agenda. Home is '*somewhere safe - the safest place*'. One professional talked about her home as '*sanctuary*'. Several factors were cited as contributing to this sense of safety and security: having sources of help, familiarity, neighbours, relationships, family, building, neighbourhood, a place of refuge. People talked about feeling safe from harm, fear, danger, emotional pain, loss of control and risks. These points were also made in relation to living in Sheltered or Extra Care housing.

In some people's eyes, there is a stigma about moving into housing schemes. There were comments about how people were not clear about the difference between housing and care homes, and one woman said that she had been very reluctant to move from her home until she had actually seen the complex and realised that she was not being asked to move into a care home. Her view, acknowledged by others, was '*that's for older people, it's not like being at home*'.

Case Study - Living with dementia in Sheltered Housing

Mrs P worked for LHT as a scheme cleaner at a sheltered housing scheme in Liverpool for many years. Mrs P liked her job and the tenants living in the scheme and got involved in activities and events going on. She saw lots of changes at the scheme and was much more than just a cleaner by the time she retired. At the age of 72 she moved into a flat in the scheme. Mrs P already knew lots of her neighbours and had some really strong friendships. X was a strong independent woman, and moving into the scheme didn't stop that. X had a great social life, she was actively involved in the scheme but also continued to be found in Mathew Street with her best friend (who also lived in the scheme) on a Saturday night!

It was the scheme manager and her friends who first started noticing a change in Mrs P. it was becoming apparent that there was an issue with her memory. The scheme manager spoke with her family member and raised concerns. The scheme manager encouraged Mrs P and her family to discuss the problems with her GP.

Mrs P got great support from her neighbours who kept her involved in scheme activities. There were a few occasions when Mrs P found herself lost very near to the scheme and was brought home by members of the public. Her friends and neighbours would see her on her way out and would encourage her to go to the lounge. This worked well for a time.

Despite losing some of her memory Mrs P always remembered her work at the scheme and could talk in detail about how the scheme had once been, the floors she used to polish and the warden who used to manage the place. Her memories could lift her mood.

Ten years after moving in to the scheme Mrs P's dementia had developed considerably and she had started to put herself at risk by some of her actions. Mrs P moved out of the scheme at the age of 83 and left a great gap for tenants and staff alike.

Links to evidence base and best practice

Such illuminating conversations have yielded valuable insights into what matters to older people and people with dementia in relation to 'home'. In this section, we link the themes that emerged from the conversations to current evidence and best practice, to help identify what will be useful learning for practitioners, commissioners and policy makers.

Sense of identity and the relationship with home

One of the challenges posed by dementia is that of retaining a sense of identity, when the thread of our personal narrative is lost and interpersonal relationships become compromised. People with dementia will continue to try to make sense of the world, but sometimes their reality may not correspond to that of others around them. This may add to difficulties in personal relationships.

Recognising the importance of maintaining a sense of identity requires a number of good working practices including:

- person-centred care
- a biographical approach
- the involvement of the wider community
- relationship-based care and support
- a rights based approach

Relationships and social connectedness are of critical importance. Kitwood's model of dementia which endorsed personhood and the sense of self has been developed by Nolan et al (2006). They have advanced the concept of '*relationship-centred*' support. The 'Six Senses' model brings the senses of security, continuity, belonging, purpose, fulfilment and significance into a model of caring relationships. This rang true with older people and carers as they described the relationships that create a 'home'.

Some people expressed the desire for equal relationships and for their views to be valued. This entails the expectation of working co-operatively with a view to realising people's aspirations. Sabat (2002) noted that a strong sense of identity is bound up with recognition of people's significant roles, and that neurological deterioration is hastened if these are not sustained.

Older people were clear that having a home as a base was a vital contributor to their well-being. In a report published by Lloyd and Parry (2015), 80% of older people stated their wish to remain in their own homes and 85% to remain in their own neighbourhood, emphasising the importance of 'ageing in place'. The HAPPI3 (2016) study also identified this need to 'age in place' and the importance of a home for life for people who develop dementia.

Older people expressed the need for privacy in their own space to undertake intimate and personal activities. They tended not to extend this view to shared spaces. HAPPI3 noted that to reduce costs, some housing providers have increased communal spaces to slim down the private space in people's own accommodation. The decoration of place can also be controversial, as housing providers may pay more attention to design than to people's histories, or may disregard design features that are important to disabled people.

The needs of people who develop dementia early in life face challenges which differ from those of older people. They may be living with a young family for whom they have active family responsibilities and may be in employment, or they may have had to leave their job – a more likely scenario. Support offered needs to recognise these differences and include relevant activities and opportunities. People's spouses or partners may now have to earn money as well as provide care and support. The diagnostic process may take longer for a younger person for a variety of reasons such as mis-diagnosis as stress, depression, menopause and hormonal changes.

Current thinking is that all people with Down's syndrome will, in later life, develop the physiological symptoms associated with Alzheimer's disease, but the symptoms may not show the patterns characteristic of dementia (Bush and Beail, 2004). By using a disability rights approach, environmental factors can be assessed as contributory factors to their experience.

This project's findings accord with those of the ENABLE-AGE study (Sixsmith et al, 2004); psychological needs are met by feeling safe and secure, by individuals having their own space for privacy and living the lives they choose. 'My Home Life' (Help the Aged, 2006)) is aligned with these findings. Home can be a refuge, it can provide the comforting continuity of place, location, objects, memories, relationships – all of which are crucial for people with memory loss and dementia. The prospect of having to relinquish attachments to place and possessions consistently evoked painful feelings.

Locality and belonging matter to us. People were united in endorsing the importance of community, whether it be by location, ethnicity or class, to a sense of home.

Transitions

'To be rooted is perhaps one of the most important and least recognised needs of the human soul'

Simone Weil

People move in later life for a variety of reasons such as bereavement, deterioration in health, increased frailty and dependence, a change in personal circumstances (e.g. a partner or spouse no longer able to cope with caring responsibilities), for support, to be nearer to family or to free up finances. Often it is a move that is triggered by distressing events.

The project identified a variety of reasons for people's transitions. For some, changes in their neighbourhood and the need for greater security and companionship had led them to consider such a move. Significantly, most people were pleased to have made the move.

Tadashi Toyama (1988) sought to understand the complexities of moving in later life. He found that those people who moved only a short distance were better able to cope with the change. Those who were able to recreate the interior of their old home, or find a familiar layout of rooms, were able to maintain their daily routines better. The people in this Swedish study who had a more active role in both the decision to move and the actual moving process were much more likely to adjust well.

An issue raised by several people was that of being uncertain about what housing options were available, if they were to move. In talking with housing providers, there was variability about the extent of the information that they provided as well as the quality of support provided to people considering a move from their homes. Increasingly, the requirement for making a housing application is on-line, with little or no support available to do this. The 'My Home Life' project identified the need for good quality information as well as staff who have time to give people so that they have a real sense of what to expect if they move. The issues raised in our study should be considered when producing information.

Support to settle is also crucial. Some people described situations where established tenants had been unwelcoming and this had made their transition difficult. Others told us of problems with neighbours and how having felt unsafe in neighbourhoods with changing demographics and developments became the impetus for their relocation.

A message from this project is that whilst home has many positive characteristics for many people, it can also hold the opposite for some. A woman who had experienced devastating ill-health after the death of her husband consequently felt unsafe in her home environment. Moving to extra care housing has given her a new lease of life and a freedom that she had lost in her old home.

Planning for the future must address those things that matter to us. This project endorses Levy et al (2012), *'traditionally preparations for retirement have focused on financial matters, but... psychological preparedness also deserves attention'*. Professionals responsible for delivering post-diagnostic support confirmed that they do not currently include specific opportunities to explore housing matters and whether current arrangements will remain suitable as people's dementia progresses. Julie and Phil Dickinson's story illustrates the importance of finding an architect who understands dementia; they were fortunate, but others may not know where to look for one. The SURF group advised that such discussions about housing would be helpful and, as a result, invited a housing representative to come to a future meeting to describe the options available.

Finally, there is no doubt that there is a shortage of suitable housing for an ageing population. According to the Department for Communities and Local Government, estimates suggest that there is a shortfall of 45,000 housing units a year of specialist housing for people with varied support needs. In addition to this, although 76% of those over 55 own their own homes, two million older people live in 'non-decent homes', that is homes that have a serious health hazard putting the occupants at risk. With a consequent cost to the NHS of £1.4b a year (Nicol et al., 2014). Involving the housing sector in planning for older people is therefore part of the solution. It is also vital to involve older people, people with dementia and carers in discussions about housing developments, whether in the public or private sectors, to avoid the danger that housing will be developed that they do not want to move to. As Tony Watts (2016) suggests, there is a keen interest

in building intergenerational housing communities that encourage interdependencies, building on the strengths of all generations.

What makes the sheltered housing scheme a good place to live with dementia?

- The scheme manager who has had training and experience of dementia makes daily welfare calls to each tenant and works to ensure that tenants are living in a healthy, safe environment. The scheme manager can make referrals for care services, adaptations and benefits advice. They also encourage involvement and social activities to help reduce isolation. They work in partnership with GPs, social care, and families to help support the person living with dementia to live well in their own home. They can offer practical advice and solutions for those with the onset of dementia such as post-it note reminders, labelling of drawers, having a diary or calendar for all appointments and key chains. They use toolkits to help improve someone's home, such as removing rugs and patterned carpets, improving lighting.
- The 24 hour lifeline alarm and mobile response service enhance the service when the scheme manager is not in work. Each tenant has a lifeline alarm, pendant and inactivity monitors and can benefit from other technology such as falls monitors, flood alerts and door sensors, depending on individual needs
- Living with other older people who have similar life experiences – particularly if the person develops dementia whilst living in sheltered accommodation; friends in the scheme are very supportive and are familiar faces.
- Level access accommodation with lifts to all floors – people with dementia may have other health problems. Stairs can become a problem due to changes in visual perception.
- A tenant has their own flat with their own front door – a person's own belongings, whether furniture or photos in their own home can bring familiarity particularly if the person living with dementia moves into the scheme. These objects can help someone to feel safer.
- Safe and secure environment with CCTV, secure door entry. The schemes, while having a stay put policy, have very sensitive fire alarms which means incidents are responded to quickly, keeping everyone safe. The schemes have pictorial signage to help navigate the building.

Isobel Godwin, Liverpool Housing Trust, Nov 2016

Implications

An aim of this project is to develop awareness amongst professionals about the issues that people have told us are important to their sense of identity in relation to 'home'. A common thread is the need for staff to understand and recognize legal requirements relating to disability and discrimination and for people with dementia and their carers to be more informed about their rights and entitlements, so that they can advocate on their own and others' behalf. The implications for specific groups include:

People with dementia

People with dementia had had little, if any opportunity to discuss the meaning of 'home' and its importance in formulating their sense of self and what matters to them. Our project spurred some people into realizing that such considerations are important and could be helpful in terms of making sense of their circumstances for their own benefit and also help to prepare them should their circumstances change. They want opportunities to articulate their needs and wishes to professionals who may have other plans for them. Too often, assessments of need take place as a result of crises or change of circumstances. Although people with dementia and carers are expected to defer to clinical advice that admission to residential care is necessary, this may occur without reference to how they were managing prior to hospital admission. Most people do not elect to go into a care home.

Good post-diagnostic support includes information and advice about financial affairs, making a will and lasting power of attorney, but rarely housing options. People explained that the earlier you start planning, the easier the process of moving. Dedicated time within a post-diagnostic support programme would encourage people to think about their housing needs whilst they are still able to make positive choices.

Although there is a raft of information about staying independent at home and possible housing solutions, produced by organisations such as Independent Age, Age UK/Age Cymru, Alzheimers Society and Elderly Accommodation Counsel, many older people and family carers do not know where to find it. A basic leaflet giving details of where such information can be found could be provided to people at the point of diagnosis.

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. They, too, would benefit from such discussions within a post-diagnostic support programme,

The right to an assessment of need in their own right was re-affirmed in the Care Act 2014. Such assessments should include consideration of housing need and the significance of 'home' for the carer. Many carers draw support from neighbours and friends, who may be vital lifelines in terms of emotional support, social contact and informal respite arrangements. 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.

The main responsibility for organizing a move will probably lie with the carer. Whilst our case studies of the Gilberts and the Dickinsons are examples of joint planning and decision making by both couples, Eileen and Julie had to take the lead in implementing their decisions.

Hospital discharge teams

These staff are crucial in 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 home – both the place and the people – so that appropriate help and advice can be offered.

A rights-based approach should be reflected in assessing and managing risks. Hierarchies within hospital settings persist. Once a doctor has told an individual – or more likely their carer – that residential care is required, it is difficult for other professionals to retrieve a position of exploring the option of a return home with additional support and for the individual concerned to articulate their preferences honestly, without worrying about what response they will get.

For people who lack capacity, Best Interest Decisions are required. Staff involved must make sure they find out as much as they can about the individual's known wishes and aspirations and living circumstances prior to hospital admission, not just during the crisis period that may have led up to it. Using a rights-based approach should enable a balanced appraisal of the risks in returning home and being admitted to residential care for example. Although we know that people do not receive individual care for 24 hours a day and that living in a care home will not stop people falling, these arguments are typically advanced as reasons why people cannot return home. This project underlines the need for negotiated support planning and decision making.

The contribution of housing staff to discharge planning may be overlooked. Although they have valuable information about individuals and how they were managing at home, they are rarely involved or regarded as informed professionals. Yet assumptions may be made about what sheltered or extra care housing provide without checking these out 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 in terms of: local housing and support options; access to these options; changes in benefits linked to housing; and eligibility criteria for Disabled Facilities Grants. Building professional networks with local housing providers will bring benefits not only in terms of knowledge of resources but also in mutual trust and confidence in when planning for and with individuals.

Social care assessors

Our findings indicate that those undertaking social care assessments should introduce the topic of housing needs at the earliest opportunity. As a hospital social worker observed, often referrals for supported housing come too late when people's needs have become more complex and the most likely outcome is residential care. An earlier move to more appropriate accommodation, with additional support, could mean that changing needs can be responded to more easily so that the person is able to live longer in their own home. This underlines the importance of staff having an understanding of the significance of home, place and associated relationships.

Exploration of housing during the assessment process should include information about all possible options, including adult placements, group living, sheltered housing and extra care housing. Assessors should also be able to point people in the right direction for advice on legal and financial matters.

Participants in a multi-agency workshop suggested that although integration at a strategic level has brought major benefits, such as shared budgets and clear joint strategies, it is not safe to assume that the same level of shared information and joint action is taking place amongst practitioners. Porous professional boundaries may create the risk that each assumes someone else is talking to people about the detail of their home circumstances and what matters to them.

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. However, we heard that tight budgets, long waiting lists and the progressive nature of dementia may make some OTs reluctant to commit to major adaptations in an individual's home; their professional judgement may be that benefits for the person may be too short term, either because of the length of time before the work is completed or because their cognitive decline has advanced too far, and are therefore outweighed by the costs of the work.

The Mental Capacity Act provides a legal framework for assessing if people have capacity to make specific decisions and a process for making Best Interest Decisions. Signing up for tenancies – and relinquishing them – should be subject to these procedures, so assessors should familiarise themselves with the expectations and requirements of housing providers. In such circumstances, some local authorities are, understandably, reluctant to act as guarantors for tenancies.

Housing staff

Our project encouraged housing staff to think about the information they have about their provision and the degree of contact and advice they give at critical points: that is application; offer; moving in/induction; and follow up/review. Some Registered Social Landlords had 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. Given that some families feel the need to disguise the extent of their relative's dementia for fear of jeopardizing the offer, this poses 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 care-giver has died. Also, it should be remembered that some people do not have families to support them through the process, so housing staff may need to assume a more active role. Clear information and pro-active dialogue at the point of application would provide a compelling benchmark by which the discussions at the offer stage could be measured. It is appreciated that this has resource implications, but the housing participants thought that this would be an investment worth making if it reduced the amount of work, distress and upheaval generated by inappropriate re-locations.

Introducing new residents into schemes can be a difficult process, especially if most residents have lived there a long time; schemes without a warden may be slow to identify emergent problems. The suggestion of a 'settling in pack' was made. Housing staff acknowledged that some colleagues are not as empathic and person-centred as they should be and emphasized the need for bespoke training about dementia and its impact on the person diagnosed and their carer. They made the point that 'Dementia Friends' is a good start – but as very basic awareness raising it does not give staff the tools and techniques to work directly with people with dementia.

Given the observations of the OTs, housing leaders have a responsibility to make sure that housing developments incorporate dementia-inclusive features, such as lighting, signage and bathroom fittings, at the design stage. There are plenty of materials available to assist, such as those produced by Stirling University Dementia Services Development Centre and the Kings Fund.

Finally, there was a mixed picture concerning the input of the housing sector at a strategic level. Although there is representation on the Health and Well-being Boards, there was general agreement that joint working at operational level was lacking. Housing staff did not believe that they had a 'seat at the table' so were not regarded as equal professionals by their health and social care colleagues.

Commissioners

Our discussions with professionals confirmed that there are significant gaps in service provision, with a continued reliance on what already exists rather than finding creative solutions. Given the current difficulties of people being admitted to hospital in crisis and having to wait for social care resources to become available, it was suggested that investment in services to enable people to return home with intensive support, rather than deteriorating as a result of prolonged hospital stays, would elicit much more realistic assessments of people's abilities and strengths in their home environments, rather than reliance on assessments in the false setting of acute hospitals. In the light of our findings, participants in the multi-agency workshop suggested that we should be 'commissioning for home', to highlight the need to address the importance of 'home' and what it means to people. This would crystallise what person centred care means and how it can be provided more effectively, for example home based respite care rather than a choice limited to care homes. It would also support discussions about home and what it means at a much earlier stage so that people could plan their transitions ahead and reduce the likelihood of crises occurring.

There was a strongly held view that commissioners need to test out their assumptions about what is being provided. For example: what are the components of post-diagnostic support? Are people with dementia and carers offered a structured programme that includes the opportunity to explore housing options, as well as financial planning and legal matters relating to lasting power of attorney and making a will? What level of individual support do people actually receive in residential care?

The Care Act has given local authorities a duty to shape the care market to meet the needs of their local populations. They should include groups from all communities in their commissioning strategies: black and ethnic minorities, LGBT, people without children, people with learning disabilities and people with young onset dementia. Continuing to commission solely on the basis of a deficit model – what people can't do – rather than one that also supports active citizenship, builds on strengths and recognises the value of social relationships, is no longer viable. Housing has a key role to play in this regard both strategically and as part of service provision to meet individual needs.

"This session has really helped me to shine a light on the whole issue of 'home' and realize that home is inextricably linked with your identity and wellbeing – in fact I can now see that 'home' is the umbrella under which all other health and social care needs sit. We need to get this right".

Participant in multi-agency workshop

Conclusions and Recommendations

This project has explored matters of profound significance to all of us - living independently for as long as possible, with people we love, in a place of our choosing. Moving house is a layered and difficult transition which can be immeasurably worsened for someone with memory loss or other cognitive difficulties, especially if the move was not intended or desired. The provision of appropriate and timely support in the familiarity of our homes may prevent and reduce costly hospital admissions or admissions into care homes. Other risks attached to making an unplanned or unnecessary move include social isolation and the erosion of identity and independence, most particularly for people with dementia.

When older people, people with dementia, family carers and professionals had the opportunity to think about what 'home' means, this was highly valued. It illuminated matters that they had not thought about explicitly before. It highlighted the responsibility of professionals to create similar opportunities as they assess people's needs, particularly at times of crisis.

However, home is not a positive place for everyone. Even though our homes are where we should be most safe, for some people home became a place of fear, of sadness, abuse, a place of memories that hurt. It follows that discussions about identity and home must be sensitive to the context of culture - not just by ethnicity, but also to people from LGBT communities, people without children, people with disabilities and people with young onset dementia for example.

Multi-disciplinary working is crucial in ensuring best outcomes. Where people are living in social housing, staff involvement can ease transitions. Unfortunately, many housing providers have withdrawn managers from sheltered schemes as a result of cuts in Supporting People funding and have replaced them with neighbourhood or area coordinators/managers whose remit is far wider. This project confirms that where they still exist, they play a significant role in facilitating transitions for new residents, guiding people through the application and acceptance processes and brokering their introduction to existing residents.

Supporting people to make decisions about moving home is especially important during a crisis, such as an unplanned hospital admission, when people with dementia and their families may find themselves being rushed into deciding that admission to a care home is necessary. Such moves may be promoted by professionals who have little understanding of how well the person was living with dementia at home before the crisis struck; they may also have little knowledge of what support services are available to enable people with dementia to continue living in their own homes. The concept of home and people's relationships to home are complex and situated. There is an understandable wish for us to have somewhere we can '*throw down the handbag, kick off the shoes and relax*' in whatever way we choose to, where we can feel in control of our lives, somewhere that is sustaining emotionally, physically and spiritually.

'It is clear that mental health is more than the absence of illness. To be mentally healthy requires positive psychological functioning, which is a product of a person's satisfaction with life and happiness, and their personality resources such as self-esteem, competence, control and resilience' (Cattan, 2009).

A truly person-centred approach recognises individuality in the context of culture and socio-economic situation. It requires empathy and an understanding and application of the principles of compassionate relationship-centred care. Continuing professional development for people working with people with dementia should reinforce people's self-identity and nurture an understanding of the importance of home to all of us.

Since dementia is a process that undermines the *'ability to preserve a sense of themselves as a unique and valuable being'* (Cheston and Bender, 2003) supporting people to plan ahead in advance of significant cognitive challenges developing may enable consideration of housing options. This may include adaptations to their existing property, moving to more accessible accommodation or re-locating to be nearer family members.

The project shows how the maintenance of memories, cultural activities and values and familiar relationships play a significant role in self-identity and consequent well-being. These insights are relevant to professional practice which aims to achieve positive outcomes both for people and economic benefits for health and social care.

Finally, our findings confirm the crucial role that housing plays in supporting people with dementia and carers. The sector should be included as an equal partner in planning and designing services for older people as well as a significant player in service provision.

'Social care, health and housing are three legs of a stool. Underinvest in one, and the stool can only wobble on two legs for so long ...'

Watts, (2016)

Key Recommendations:

The Life Story Network is proactive in sharing valued and insightful practice and we propose to share this report across our networks. It is our view that the following recommendations will be useful in tilling the ground for productive discussion and developments.

1. This report should be distributed within NHS England, Public Health England, ADASS, the LGA, Dementia and Housing Working Group, the Carers Trust and other key voluntary sector organisations to highlight the importance of 'home' and its relationship with identity and well-being, in particular for older people, people with dementia and their carers
2. After a diagnosis of dementia, support programmes should include opportunities to consider people's homes, their housing needs and planning for the future, alongside financial planning, making a will and having a Lasting Power of Attorney for example

3. NHS and social care assessors should include discussions about what home means to individuals to inform their assessments, care and support planning and risk assessments
4. Registered Social Landlords should review the information that they produce about the types of housing they offer and ensure that these are described in straightforward language, They should also set out what potential residents can expect in sheltered housing, extra care housing and group living schemes for example, and should consider a "Settling-in Pack" for new residents. Their information should ensure that people from particular communities, e.g. LGBT people, those from minority ethnic groups and people without children, feel welcomed and that their needs are of equal importance.
5. Registered Social Landlords should review their processes in relation to - applications for accommodation, making offers, signing tenancies, induction into properties and reviews of tenancies - to ensure that all options are explored and explained fully. This should smooth transitions and mitigate the distress associated with having to move, minimise the risk of moving into unsuitable accommodation and identify emerging problems as early as possible
6. Health and social care commissioners should be encouraged to start 'commissioning for home.' This should make explicit the importance of home in relation to our identities and well-being
7. Registered Social Landlords should include in their workforce development plans bespoke training on (i) the impact of dementia on people who have been diagnosed (ii) the impact on their relatives and friends and (iii) the ways in which housing professionals can support people to live well with dementia
8. Registered Social Landlords should be included as equal partners in planning forums for older people, people with dementia and carers
9. NHS bodies, local authorities and Registered Social Landlords should ensure that older people, people with dementia and carers are involved in strategy development and service design, including housing developments
10. Commissioners, NHS Trusts, local authorities, social care providers and Registered Social Landlords should satisfy themselves that the services they are commissioning and providing are compliant with the Equalities Act and the Human Rights Act, particularly in relation to people with dementia. They should make sure that policies in relation to adaptations, for example, do not inadvertently discriminate against people with dementia.



BEYOND THE FRONT DOOR: What 'home' means to people with dementia and their carers

LITERATURE REVIEW *Appendix 1*

An extensive literature search underpins this project exploring issues of identity in dementia, the meaning of home, particularly to older people and the work already undertaken in the area. We also consider home in relation to person-centredness and identity.

Search terms:

dementia, identity, home, housing

'Identity is the sense of who one is in the world, distilled from a lifetime of experiences. From the collective perspective, identity consists of the life course as a cultural construct: socially normative and collectively outlined and accepted life course statuses and transitions. But at the individual level, every person creates for herself a particularised version of the collective life course, a life story, depending upon her specific experiences and the meaning she attaches to them' (Rubinstein, R.L. & Parmalee, P., 1992)

'The construction of a coherent, united sense of self is an ongoing process. We have seen how old people express an identity through these which are rooted in personal experience, particular structural factors, and a constellation of value orientations....The sources of meaning which themes integrate are continually reinterpreted in light of new circumstances. A person selects events from his or her past to structure and restructure his or her identity. Thus, themes continue to evolve from and give form to personal experience - making identity a cumulative process' (Kaufman, 1986). Mayer et al (1999) argue that older people are just as or even more strategic than younger people in constructing identity.

'We have each of us a life story, an inner narrative whose continuity, whose sense, is our lives. It might be said that each one of us constructs and lives a 'narrative' and that this narrative, is us, our identities. To be ourselves, we must have ourselves - possess, if need be, re-possess our lives stories. We must re-collect ourselves; re-

collect the inner drama, the narrative of ourselves. A man needs such a narrative, a continuous inner narrative to maintain his identity, his self' (Sacks, 1988)

Much has been written about the need for people to remain in their own homes for as long as possible and indeed this is the vision of current dementia strategies (National Dementia Strategy, Dignity initiative, Personalisation programme, Intermediate Care initiatives...). These strategies, documents, and guidance have been developed to assist with maintaining people in their own homes for as long as possible and reducing the possibility of transition from home. The emphasis however is on minimizing risk and on practical issues. The personalization agenda has encouraged life story work and the need to know about preferences and life history in order to offer personalised support to meet those individual needs and preferences. However, there is a distinct lack of knowledge and appreciation of the importance of 'Home' to us all. Without this deeper psychological understanding of the importance of home, people's needs are not being met in a meaningful way.

'Post diagnostic support for people living with the effects of dementia and their families and carers should be personalised, flexible, culturally relevant and have proper regard to equality. There is no one size that fits all, with different needs existing according to personal wishes and circumstances, the nature of the dementia and the course of the condition. The whole person needs to be considered, taking into account any co-morbidities, allowing them the opportunity to have the choice and control to manage their condition as far as possible and to live as well as possible with dementia.' (DH, 2016)

Since 2012 diagnosis of dementia has increased 50%. The household projections of the ageing population suggest that by 2037 over a third of households will be over 65 (Shanks, 2016) and with more than a million older people in Britain claiming to always or often feel lonely (Wood, 2016), increasing opportunities to embed healthy living into everyday lives makes both economic and social sense. 'According to recent estimates investing £1.6bn annually in housing-related support services generated net savings of £3.4bn for the public purse' (Jabbar, 2016).

The very idea of home is inseparable from our sense of self, and our sense of identity. 'Our home is our base, a places that roots us to the earth, to the city or the landscape; it gives us permanence and stability and allows us to build a life around it and within it' (Heathcote, 2012). The findings of the ENABLE-AGE project, which explored the relationship between home and healthy ageing, indicated that 'an understanding of healthy ageing requires a deep reflection on the ways in which ageing psychological, social and biological processes are integrally linked to the physical environments of home and community'(Sixsmith et al 2004).

As Cooper Marcus (2006) notes 'A home fulfils many needs: a place of self expression, a vessel of memories, a refuge from the outside world, a cocoon where we can feel nurtured and let down our guard'. And John Bond (1993) adds 'As people age they become more orientated towards home; it is seen as a refuge and becomes increasingly important as other social roles in later life are relinquished'.

We must not forget however, that 'home' is not always a safe place or a place of good memories. The location, memories of abuse, fear, sad times - a myriad things may have happened that mean that a person may not have a good sense of 'home'

or even know what ‘home’ means. A home that lacks positive meaning ‘provides no sense of security, order, identity, connectedness, warmth, or suitability (Gifford, 1996, p.197, in ENABLE-AGE, p.7)

One of the most influential factors in all our lives is the environment in which we live and home provides a major focus in life. ‘As people age they become more orientated towards home; it is seen as a refuge and becomes increasingly important as other social roles in later life are relinquished.’ (John Bond, 1993)

Home can mean different things to different people - for example the situation for immigrants, people in low income housing and home owners - their expectations and experiences may well differ, as will emotional attachments. All this adds up to the need to really understand the perspective of an individual, in a way that enables us to recognise what ‘home’ means to them. It is only then, that we can support and address issues that have deep significance for the person when considering how best to support them, and *where* best to support them at a time of change in abilities.

We are much more aware nowadays that changing location, moving to a new place, can be disorientating for someone with a dementia. ‘It is increasingly clear that the environment in which the person with AD (Alzheimer’s disease) dwells can exert a potent effect upon his or her cognitive and behavioural abilities’ (Sabat, 2002). There is wide recognition that people with memory loss function best in a familiar environment, and this is something that most of us can relate to, although there will be exceptions for example, people who have experienced abuse or significant trauma at home. ‘The location, shape, and form of our homes impinge directly on the smallest details of our daily lives’ (Shove, 1999,) and ‘...it is increasingly clear that the environment in which the person with AD dwells can exert a potent effect upon his or her cognitive and behavioural abilities’. (Sabat, 2002). So it is of utmost importance that we recognise and understand this when it comes to consideration about whether to introduce transitions into the lives of older people and particularly if they are experiencing memory loss with attendant functional difficulties.

The Impact Framework of Robert Dilts enables insight into how significant a transition may be for a person:

- Sense of purpose - impact on people’s motivation and meaning in life
- Identity - impact on how people feel about their role and place in society
- Beliefs - impact on what people believe to be true or important
- Capabilities - how people’s talents and abilities are affected
- Behaviour - what changes might be required in the actions the person takes in their day to day life

Recently, the Parliamentary and Health Service Ombudsman (2016) wrote a critical report on standards of discharge they investigated. One of the crucial issues they discovered was the failure by hospitals to check people’s mental capacity and consequently not take into account preferences for care arrangements; secondly, a failure to notify and include families in discharge arrangements. Poor co-ordination compounds these issues and reiterates the need for better integration of services,

joint working and the sharing of important information that can make a meaningful discharge for people with a dementia.

The focus on high quality commissioning (LGA, 2015) clearly states '*What matters most to people?*', a bold statement making it incumbent on services to empower choice and control; to have the person at the centre; to set goals with people accessing services and to recognise the importance of the quality of relationships between services and those using services. It is our aim to include conversations with commissioners to develop their understanding of the importance of our findings in meeting the needs of their populations.

The importance of the quality of relationships in interactions with people with dementia is recognised in the work of many leaders in the world of dementia care, including Tom Kitwood whose work underpins much of modern dementia care. He argued that the key to supporting people with dementia is to have a deep understanding of the person as an individual, who has individual needs, a past, relationships and a place in society. There may be some commonality with others who have dementia, but above all we need to see the person with dementia as an individual first and foremost. His model was a psychological precursor to the rights-based models of today. At the same time he developed the concept of personhood in which he argued that we develop our sense of who we are in relation to others. Personhood is akin to identity and his model of Enriched Care identifying positive and negative modes of interaction contributes to a fuller understanding of the impact that relationships can have on a person with dementia.

Mike Nolan et al developed Kitwood's work further. Their Six Senses Framework identifies the subjective dimensions of caring relationships, reflecting both the interpersonal and intra-personal processes of giving and receiving care (Nolan et al, 2006). Nolan promotes this model for all those in relationship, not just the person with dementia. Following a series of healthcare investigations, a new approach of compassion based care was developed to enhance patient outcomes. This model recognises that compassion has neurophysiological impacts and that compassionate care makes interventions more effective.

Building on Kitwood's work, Dawn Brooker developed the VIPS model of person-centred care: **V**alues, **I**ndividualised approaches, understanding the world from the **P**erspective of the person with dementia and a supportive **S**ocial environment, placing the person with dementia at the centre of planning and decision-making (Brooker and Latham, 2016, 2nd edition).

On the other side of the Atlantic, Naomi Feil developed a model of Validation. Like Kitwood and others, she recognised that the sense of identity can easily become eroded in dementia and she sought to enhance the quality of life for people with dementia. Her model seeks to understand the reality of the person with dementia and she provides us with tools for therapeutically inclined ways of relating to people with cognitive impairment. This model is dependent on the empathy of the person communicating with the person with dementia and how to 'be' with the person. Being a reflective practitioner is central to being in the present with the person with dementia.

In the studies undertaken by Age UK in their Later Life series, they found that feelings of having little or no control over their lives *'statistically increased people's risk - by over three times - of rating their quality of life as bad rather than good, compared with those who felt they had a lot or some control'* (Age UK (2016))

Having the freedom to express ourselves and to psychologically invest in our environments is a key factor in making the place meaningful with consequent benefits - to comfort, sense of identity, being in control.. People act proactively on their environments, *'selecting and adapting their surroundings to enhance competence and the achievement of desired goals'* (Chaudhury, 2008).

Findings of the European-wide ENABLE-AGE study funded by the European Commission (2002-4) indicated that *'an understanding of healthy ageing requires a deep reflection on the ways in which ageing psychological, social and biological processes are integrally linked to the physical environments of home and community. As embodied and emplaced, older people draw on their meanings of home to create an environment of safety and security, privacy and comfort, adapting socially and psychologically to health and mobility related declines'*.

As people age and become less able to look after themselves, old coping mechanisms are no longer keeping people safe, and quality of life can be impaired. It is natural for others to become concerned and consider whether their relative or friend should move from their home. Many factors come into play in relation to where people, particularly people with memory loss, should live, and pressure is often brought to bear on older people to consider moving from their own home. Generally speaking, people have no wish to move from their home, and the majority of people who reside in care homes have not moved there out of choice.

'Continual engagement in life's roles and activities is a means in itself for maintaining independence' (NICE-SCIE, 2007, p.171). Social networks, voluntary services and remaining a part of one's community all contribute to maximising independence and consequently health and well-being. For older people and particularly people with a dementia, remaining in the familiarity of their own home increases the chances of being able to remain as independent as possible.

The Beth Johnson Foundation, in collaboration with Ageing Without Children (2016), have highlighted the fact that there is an increasing number of people without children in later life, and that there tends to be a lack of recognition of this fact. They point out that there are strong taboos in our society associated with being an adult without children and that people may face criticism and prejudice. In terms of considering a transition to a new housing provider, assumptions may be made about family support that doesn't exist; glossy brochures of happy families may be off-putting and increase the sense of invisibility.

Similar considerations have been raised in reports by the National LGB&T Partnership and University of Worcester and DEEP in relationship to these groups of people for whom there are also particular issues in relation to identity. The UK is home to an estimated 1.2 million older lesbian and gay people Key issues that they highlight include:

- LGB&T people with dementia have multiple identities that intersect with age, gender, disability, social class, ethnicity and individual biographies and experiences
- failure to recognise that being LGBT is more than about a person's sex life
- cultural stereotypes and assumptions e.g. excessive sexual practices and behaviours with gay male and bisexual identities
- the importance of being LGB and/orT as a central identity
- perceived risks to disclosure (and reminders of earlier experiences of coming out - older people have experiences less progressive social and legal climate)
- anguish and confusion may be exacerbated by dementia as LGBT people struggle to deal with negative perceptions
- sexual identities can change over time, particularly women's identities and dementia may impact on a person's sexual behaviour e.g. if people lose their inhibitions
- being 'out' enables challenges to practice e.g. for carers
- LGB&T older people are more likely to be estranged from relatives and lacking family support

Trans identity and dementia - particular issues include:

- may have complex social or bodily needs
- trans and Intersex people are particularly vulnerable to discrimination and may well avoid seeking or deny services
- forcible cross dressing and deliberate violences may have been an issue
- fear of judgement and discrimination by service providers
- medical issues relating to natal gender that emerge with ageing e.g. osteoporosis or prostate cancer
- a post-operative Trans woman may forget her external gender aspects and may be confused and distressed in self care



BEYOND THE FRONT DOOR: What 'home' means to people with dementia and their carers

MODELS OF PRACTICE *Appendix 2*

Definition of Well-being

In relations to an individual, means that an individual's well-being so far as relating to any of the following:

1. personal dignity (including treatment of the individual with respect)
 2. physical and mental health and emotional well-being
 3. protection from abuse and neglect
 4. control by the individual over day-to-day life (including over care and support, or support, provided to the individual and the way in which it is provided)
 5. social and economic well-being
 6. domestic, family and personal relationships
 7. suitability of living accommodation
 8. the individual's contribution to society
- (from Murray, 2014)

Kitwood's Enriched Model of Care

Tom Kitwood developed the diagram below to illustrate the basic psychological needs of people with dementia that must be met to enable them to enjoy well-being and quality of life. Tom considered 'love' to be a core requisite in maintaining personhood. Kitwood developed the following model identifying factors that contribute to the individual experience of dementia:

$$\text{Dementia} = \text{NI} + \text{H} + \text{B} + \text{P} + \text{SP}$$

NI = neurological impairment

H = health and physical fitness

B = biography and life history

P = personality

SP = social psychology, primarily relationships

Person Centred Care

Dawn Brooker, (2006) developed the model below from Tom Kitwood's *Enriched Model of dementia and* which now widely underpins all dementia care and support:

$$PCC = V + I + P + S$$

PCC = person-centred care

V = **V**alues people with dementia

I = Treats people as **I**ndividuals

P = **P**erspective of person with dementia

S = Supportive **S**ocial psychology

The Six Senses

This framework developed by Nolan et al (2006) is based on the premise that the best environment for older people is one where the six senses for staff, people and their families are met. The six senses are (adapted to be relevant to this project):

Security

To feel safe physically, psychologically and emotionally - everyone said how much 'home' should provide this.

Belonging

To feel part of a valued group, to maintain or form important relationships. The social nature of home was identified as a key ingredient what 'home' means to people in our study.

Continuity

To be able to make links between the past, present and future. For people with dementia, enabling people to access memories when dependence on longer term memory is a part of their reality is important for well-being.

Purpose

To enjoy meaningful activity that one have chosen to do, to have valued goals that are individual to one, that have been part of their life and 'who they are'. Participation in meaningful activity is recognised in NICE (2013) QS1 based on Kitwood's identification of it as psychological need.

Achievement

To reach valued goals to satisfaction of self and/or others. People in our study made it clear that they still have a life ahead of them and things that they still want to achieve.

Significance

To feel that you 'matter' and are accorded value and status. Our sense of self worth is bound up in relationships and people with dementia may need support in retaining important meaningful relationships .

(Nolan et al 2006; adapted by LSN)

The model is inclusive of everyone who is in relationship with the person being supported, so is inclusive and emphasises our shared humanity.

Compassionate Care

The Six C's were launched in 2012 and are a set of values that underpin the way that healthcare is delivered in the UK. All carry equal weight and focus on putting the person being cared for at the centred of their care.

Defining the 6Cs (NHS England)

Care

Care is our core business and that of our organisations, and the care we deliver helps the individual person and improves the health of the whole community. Caring defines us and our work. People receiving care expect it to be right for them, consistently, throughout every stage of their life.

Compassion

Compassion is how care is given through relationships based on empathy, respect and dignity - it can also be described as intelligent kindness, and is central to how people perceive their care.

Competence

Competence means all those in caring roles must have the ability to understand an individual's health and social needs and the expertise, clinical and technical knowledge to deliver effective care and treatments based on research and evidence.

Communication

Communication is central to successful caring relationships and to effective team working. Listening is as important as what we say and do and essential for "no decision about me without me". Communication is the key to a good workplace with benefits for those in our care and staff alike.

Courage

Courage enables us to do the right thing for the people we care for, to speak up when we have concerns and to have the personal strength and vision to innovate and to embrace new ways of working.

Commitment

A commitment to our patients and populations is a cornerstone of what we do. We need to build on our commitment to improve the care and experience of our patients, to take action to make this vision and strategy a reality for all and meet the health, care and support challenges ahead.

The Impact Framework of Robert Dilts

This enables insight into how significant a transition may be for a person:

- Sense of purpose - impact on people's motivation and meaning in life
- Identity - impact on how people feel about their role and place in society
- Beliefs - impact on what people believe to be true or important
- Capabilities - how people's talents and abilities are affected
- Behaviour - what changes might be required in the actions the person takes in their day to day life
- Environment - what changes may be required in their living arrangements or where they carry out their day to day activities



Validation: The Feil Method

Validation is:

- a basic, empathic attitude
- a late life theory for old-old mal- and disorientated people which helps us understand their behaviour
- specific techniques to help mal- and disorientated very old people regain dignity both through individual Validation and through Validation groups

Validation Principles

1. All very old people are unique and worthwhile.
2. Malorientated and disorientated old people should be accepted as they are: we should not try to change them.

3. Listening with empathy builds trust, reduces anxiety and restores dignity.
4. Painful feelings that are expressed, acknowledged and validated by a trusted listener will diminish. Painful feelings that are ignored or suppressed will gain in strength.
5. There is a reason behind the behaviour of very old malorientated and disorientated people.
6. The reasons that underlie the behaviour of malorientated or disorientated very old people can be one or more of the following basic human needs:
 - Resolution of unfinished issues, in order to die in peace
 - To live in peace
 - Need to restore a sense of equilibrium when eyesight, hearing, mobility and memory fail
 - Need to make sense out of an unbearable reality: to find a place that feels comfortable, where one feels in order or in harmony and where relationships are familiar
 - Need for recognition, status, identity and self-worth
 - Need to be useful and productive
 - Need to be listened to and respected
 - Need to express feelings and be heard
 - Need to be loved and to belong: need for human contact
 - Need to be nurtured, feel safe and secure, rather than immobilised and restrained
 - Need for sensory stimulation: tactile, visual, auditory, olfactory, gustatory, as well as sexual expression
 - Need to reduce pain and discomfort
7. Early learned behaviours return when ability and recent memory fails.
8. Personal symbols used by malorientated or disorientated elderly people or things (in present time) that represent people, things or concepts from the last that are laden with emotion.
9. Malorientated and disorientated old people live on several levels of awareness, often at the same time.
10. When the 5 senses fail, malorientated and disorientated elderly stimulate and use their 'inner senses'. They see with their 'mind's eye' and hear sounds from the past.
11. Events, emotions, colours, sounds, smells, tastes and images create emotions, which in turn trigger similar emotions experienced in the past. Old people react in present time, the same way they did in the past.

Applying the social model and human rights based approach – the PANEL model

To promote practical and systemic change to embed the social model of disability, a framework and process has been developed - PANEL. These principles offer a key way of ensuring that a Human rights-based approach can be incorporated in to planning and practice.

PANEL refers to:

- **P**articipation - everyone has the right to participate in decisions that affect their lives
- **A**ccountability - effective monitoring of human rights standards and remedies for breaches
- **N**on-discrimination and equality - all forms of discrimination in the realisation of rights are prohibited, prevented and eliminated with priority given to the most vulnerable
- **E**mpowerment - individuals and communities should understand their rights and be supported to participate in the development of policy and practices that affect their lives
- **L**egality of rights - recognition of rights that are legally enforceable entitlements (linked to national and international law)