Being Home

Housing and Dementia in Scotland

FULL REPORT

UNIVERSITY OF THE
WEST *of* SCOTLAND
UWS

Alzheimer Scotland
Action on Dementia

bre CD|LH

Being Home

Housing and Dementia in Scotland (2017)

Table of Contents

This report was funded by the Life Changes Trust and commissioned by Angus Care and Repair supported by a housing and dementia group. Life Changes Trust was keen to understand the role which housing plays in supporting people affected by dementia to stay at home. The Trust organised a number of events bringing together housing practitioners, health and social care professionals, the private and the voluntary sector to help identify housing's contribution. A small project group, the Housing and Dementia Group* was set up to consider what could be done to support the housing and voluntary sector to develop their contribution. The group recognised that there was a lot of good examples of what housing could contribute but that there was a real need to bring them together in one place. The commissioning of this report emerged from those discussions. The report has been produced by an interdisciplinary project team, comprising practitioners and academics, led by the Alzheimer Scotland Centre for Policy and Practice at the University of the West of Scotland.

*Housing and Dementia Group:

Judith Leslie, Manager, Angus Care and Repair

Lyn Jardine, Independent Consultant

Moira Bayne, CEO, Housing Options Scotland

Jill Pritchard, Improvement Associate,
ihub (Occupational Therapist)

Margaret Moore, Housing Consultant

Executive Summary

Executive Summary:
Housing and Dementia in Scotland: Services, support and solutions

Project aim

To develop a comprehensive overview of the current housing situation for people affected by dementia including the existing range of housing services, support and options, together with potential solutions. Following this review of the current situation, a prototype online resource has been designed. The intention of the online resource is to be a 'One Stop Shop' for people with dementia, their carers, families, housing, health and social care professionals, where they can access a wide range of information.

What we did

The project used a combination of desk based research methods to review current practice, services and policy and gathered new interview based evidence from housing, health and social care professionals and policy makers. Capturing the voice of people with dementia involved engaging with groups attending Azheimer Scotland supported dementia cafes, including carers.

The development of the prototype online resource was supported by discussion with people with dementia, including members of the Scottish Dementia Working Group, family and carers attending Alzheimer Scotland Cafes and focus groups with housing, health and

social care practitioners. The prototype online resource was created by BRE and is available at http://bregroup.com/dip/

Further details are available in the Appendix.

What we found

Appropriate housing is important for people living with dementia, family and health and social care practitioners. However, there is a dearth of evidence or information to support this key agenda, particularly for people living in private rented or owner occupied accommodation. Housing as a key consideration to living well with dementia is underdeveloped within the current integration agenda for health and social care. There is a need to develop evidence about the process and outcome of adaptations in the home, including technological innovations. Clear information and timely intervention related to housing needs and adaptations can be difficult to source. A prototype online resource was positively received by people living with dementia, family and practioners from a range of housing, health and social care organisations. At a policy level, while most strategies and policies about dementia refer to housing and many of those about housing refer to dementia, this connection needs to be far better integrated and explicit.

Key findings

- Distinct and independent policies and guidance are available in Scotland about housing and dementia. These state the importance of each topic, but all lack detail about what should be done.

- Housing and planning guidance contains some consideration about meeting the needs of an ageing population, but few reference people living with dementia.

- A higher proportion of Scotland's older people live in owner occupied than in social housing.

- There is a concern that much of this stock has high levels of disrepair and poor energy efficiency.

- There is a dearth of suitable accommodation appropriate to the diverse needs of people with dementia.

- Planning and building regulations currently do not support development of housing and services to meet the needs of the ageing population and in particular people living with dementia.

- There are numerous examples of good practice in housing and dementia, in Scotland and further afield, that could be implemented and developed.

- Housing associations lead in the development of innovative approaches, but this could be more effectively disseminated and replicated.

- Information about good design for housing for the person living with dementia is available, but not sufficiently accessible for the general population.

- Those who work within housing services, including practitioners, support and maintenance staff, identify gaps in their knowledge about how to support a person with dementia and their family.

- Very little is known about the awareness of dementia among providers of housing related services in the private sector.

- Collaboration within health and social care integrated teams is not fully realized or inclusive of the housing contribution.

- Currently, people living with dementia and their family lack information about general housing advice, support and funding.

- Given the current lack of suitable housing supply, it is important to consider how to adapt existing housing stock to meet the needs of people with dementia, across all tenures.

- All home adaptations should be considered as early as possible, to ensure the needs of people with dementia are person centered, well planned and can promote living well at home for as long as possible.

- Home adaptations should address the cognitive and psychological needs of people living with dementia as well as physical support.

Executive Summary:
Housing and Dementia in Scotland: Services, support and solutions

- The role of technology to support people with dementia at home is important. However technology is advancing rapidly and people with dementia need to be supported to adapt and use mainstream technology.

Recommendations

For policy makers:

- Align housing and dementia within policy discussions and decisions.

- Develop specific spatial planning policies to reflect the needs of people with dementia.

- Drive forward the development of 'all age housing' suitable for changing needs through life.

- Support innovative housing solutions for people with dementia in private and public housing developments.

- Ensure national dementia awareness and education programmes include housing related occupations.

- Encourage research about the housing needs and experiences of people with dementia, family and supporters.

For housing sector organisations:

- Increase new build private housing suitable for older people and people with dementia.

- Include design principles for dementia as part of planning for all new buildings and retrofit activities.

- Explore ways to implement housing innovations in private and public housing developments.

- Provide information about design and dementia that is accessible to the general population and all those affected by dementia.

- Implement the recommendations of the recent CIH funded report about the role and education of housing staff.

For health and social care partnerships:

- Recognition should be given to housing and dementia, by involvement and partnership with social and private housing representatives.

- Integration of housing in advance planning processes about future needs for the person living with dementia.

- Focus home adaptations on recognition, assessment and intervention for the person at the earliest point possible.

- Increase available information, training and support to people with dementia and their families interested in using technology.

- Provide transparent information about home assessment and sources of funding for home adaptations.

Summary

This report has identified the important role suitable housing plays in the life of the person affected by dementia, including family, friends, neighbours and practitioners. Full recognition of housing within the current movement to integration can increase the opportunity for the individual to live well with dementia. However, care must be taken to ensure the person who is the owner occupier is not disadvantaged in this process and the important work of educating the wider workforce cannot be underestimated. Listening to the voice of those affected by dementia and exploring the evidence for interventions to maintain the person at home is essential to future development. More clearly signposted advice, information and support can take forward the impact of housing on living well with dementia. This is addressed here by the development of a prototype online resource and website architecture to outline the headings and content of each section of the proposed website.

Chapter 1

Introduction:

This report explores the underlying evidence, exposes some common assumptions and a range of policy and other current influences shaping current housing services, support and options available to people living with dementia. Alternatives and future options, including a prototype online resource, are also suggested to encourage innovation and discussion. This report offers a range of views, ideas and evidence to inform and progress the debate in Scotland.

Chapter 1

1.1. Background

There are approximately 90,684 people living with dementia in Scotland (Alzheimer Scotland, 2017). The majority of these are likely to be older people experiencing a range of other long term conditions. Information about the role of housing services in dementia is limited. Yet the move to care at home for the person living with dementia has made involvement of housing and housing professionals essential. Integrated systems, including housing services and support are crucial. For future planning it is important to appreciate that most people, if diagnosed with dementia, would prefer to continue to live in their own home, yet around one third would not know where to access information about how to make this possible (Alzheimer's Society, 2014a).

1.2. Understanding dementia

Dementia is an umbrella term used to explain the features that result from a range of different diseases. The World Health Organization (WHO) (2016) define dementia as: "a syndrome in which there is deterioration in memory, thinking, behaviour and the ability to perform everyday activities". Impairment of memory is considered the most prominent feature found in most people with dementia, together with other cognitive deficits in language, comprehension and functional ability. The most common causes of dementia are Alzheimer's disease (62%), vascular dementia (17%) dementia with Lewy bodies (4%) and frontotemporal dementia (2%). It is also possible to have more than one of these conditions at the same time and this is called mixed dementia (10%) (Alzheimer's Society, 2014b). Most of the diseases that cause dementia have some common features but each individual who has dementia will have a unique experience. This experience will change over the course of the condition and will be affected by a range of physical, psychological, and social influences.

Dementia will most commonly occur in people who are 65 years and older but can occur in younger people. Meeting the needs of the person with dementia who is older must take account of the ageing process (van Hoof et al, 2010). This is particularly important in the design of connections and communities that support older people (Bookman, 2008). In 2012, there were approximately 190,000 households with one older adult 75 years and older, almost three-quarters of these were women (National Records of Scotland, 2014). As people age, health and wellbeing become increasingly dependent on the adaptation of the home environment and this impact of age related change is not always fully appreciated. Gender is another issue generally not addressed, although older

men living alone have been identified as facing greater challenges in sourcing social support than women (Milligan et al, 2013).

Of the 90,684 people living with dementia in Scotland there are approximately 3,200 under the age of 65 years (Alzheimer Scotland, 2017). In the UK around 40,000 people are diagnosed with younger onset dementia (Alzheimer's Society, 2014b). This group of individuals are more likely to still be in employment, have dependent children, more financial commitments including mortgages, and have less additional health problems than people who are diagnosed after retirement age (Tolson et al, 2016). Research highlights the need for specific services for people with young onset dementia (Gibson et al. 2014). This group may have different views about the process of adapting their homes or preferences for the types of adaptations they would use. People with Down's syndrome are also likely to develop dementia at a younger age and many, who may have in previous periods been supported by family, now live more independent lives and should be considered within this younger age group.

1.3. Living arrangements for the person with dementia

There are approximately 61% of people with dementia in the UK living in mainstream housing with the remainder living in care homes (Alzheimer's Society, 2012; Alzheimer's Society, 2014b). While the person with dementia who lives with other family members accounts for the greater proportion of the community dwelling group (National Records of Scotland, 2014), UK wide estimates suggest that one third or 141,462 people with dementia live alone (Miranda-Castillo, Woods and Orrell, 2010). In comparison with Scotland's estimated total of 90,684 people living with dementia (Alzheimer Scotland, 2017), there are likely to be over 55,000 people living at home, with around 20,000 people living alone (Miranda-Castillo, Woods and Orrell, 2010). The person living alone is more likely to be female with a lower income and while some may have support, others may have no circle of family and friends (Alzheimer Disease International, 2014; Duane, Brasher and Koch, 2013).

Support for carers is a key aspect of Scottish Government policy, reflecting the drive to support the person living with dementia at home (Scottish Government 2010; 2013). Housing issues may be different for the carer and the person living with dementia. It is important to consider that the housing,

Chapter 1

social and health costs to the carer are balanced with the financial benefits of informal care to the economy. It is estimated that unpaid carers contribute £11.6 billion a year to the cost of caring for people with dementia in the UK (Alzheimer's Society 2014b).

1.4. Housing and dementia

Housing staff and organisations are very well placed to take a key role in supporting the person with dementia to live well. Recognising the complexity and diversity of the needs of people affected by dementia, housing should be part of an integrated service playing their role to the full. This should form a pathway, working with the person from the earliest possible stage, even before diagnosis, through changes and adaptations over time. Part of this role is also to respond quickly during periods of sudden change, often related to ill health, where there has to be a co-ordinated and truly integrated housing, health and social care response.

Chapter 2

Living Well with Dementia

It is not only possible, but also desirable for the person with dementia to live independently in the community, particularly where diagnosis has been made sufficiently early in the illness. When this happens, it allows the person to build on current connections and relationships and prepare for the future, potentially increasing choice and making living arrangements and other changes in good time. This could avoid crises and distressing experiences. However, it is important to understand that each individual will have a singular experience. Housing and housing support must take into account the diversity of opportunities and challenges around supporting the person to live well with dementia.

Chapter 2
Living Well with Dementia

2.1 The impact of living with dementia

On the opposite page are outlined some of the situations that might occur for the person living with dementia. Not every individual will experience all of these but some responses may have an important effect on housing issues.

"I do the same things. I go out to the garden, work away in the garage, things like that, I'm very active. As far as I am concerned I have dementia and I can't stop it but don't like it stopping me either."

Angus who lives with dementia

Early involvement of the person with dementia provides an opportunity to contribute to the decisions made about changes and adaptations.

Flexibility is needed to address needs that could range from supporting memory and managing risk to practical adaptations for fundamental activities such as eating and drinking or washing and dressing (van Hoof et al, 2010). Meeting the diverse housing needs of an individual with dementia living at home is challenging and research shows a high level of unmet needs related to personal safety, lack of meaningful activity or direct personal and practical support (Black et al, 2013; Miranda-Castillo, Woods and Orrell, 2010). A forward planning and flexible needs led approach is key to decisions about the home. Early involvement of the person with dementia provides an opportunity to contribute to the decisions made about changes and adaptations (Simmons and Atkins, 2013).

Living at home with dementia can create risks for health. There are higher rates of hospitalisation in people with dementia, often related to avoidable falls (Benner, Steiner and Pierce, 2016), particularly for the person living alone (Soto et al, 2015). Good support from others and better adaptation of living environments to meet physical, cognitive and sensory changes could contribute to preventing unnecessary hospital admission (Dawson et al, 2015).

Living well is a key ideal in supporting people at home but consideration must also be given to the person who can no longer have their needs met in that setting. Despite support some people with advanced dementia may be unable

Dementia related change	What might happen?	Possible responses
Memory	The person may forget more recent events.	May forget to turn off appliances or equipment in the home.
Understanding	Increasing difficulty in organising tasks and activity.	May have problems with finances or making appointments.May have difficulty using new adaptations or appliances.
Stress	May be more easily upset or may become less involved with others.	May not respond to offers of help. Changes within the home may be upsetting.
Behaviour	May feel unfamiliar with their usual surroundings. Some individuals can be less inhibited.	The person may leave their home apparently without a purpose. Sometimes behave in ways others do not understand.
Communication	May be a difficulty finding the right words. May speak less than before.	May be difficult to identify the person's choices and provide support for decision making.
Perceptions	May say they can see, hear or believe things that others cannot.	May be difficult to know what the person is experiencing and identify how to help.

*ADAPTED FROM DEMENTIA: FINDING HOUSING SOLUTIONS.
NATIONAL HOUSING FEDERATION (2013)*

Chapter 2
Living Well with Dementia

to survive at home alone (Alzheimer's Society, 2013; Svanstrom and Sundler, 2015). There may even be greater risks in delaying a necessary move to residential forms of care for the person with dementia. Therefore a move to a care home should be considered part of the continuum of the person's housing experience.

"My sister in law has dementia, which is at quite an advanced stage. She lives at home and is cared for by her son. She wanted to stay there, when she could still tell us, but I wonder now as her home has shrunk to one room. Her bed and chair are in the living room and the rest of the house might as well not be there. I sometimes wonder if it matters to her where she is living, as long as there are people who love her to look after her. The family and carers are all she responds to now."

Marie, Family member

2.2 Decision making and dementia

The ability to make decisions can vary from person to person and is variable throughout the course of the illness. The person may be able to decide about where they might wish to stay but unable to make arrangement for repairs to the home. Capacity, therefore, is an important concern in housing decisions. Key elements that must be taken into account for every decision are:

- whether the adult understands the information given and expresses a consistent view.

- if they consider choices, reason and can make a decision.

- whether they are free from undue influence by others.

(Scottish Government, 2000)

Legislation in Scotland provides protection for the safety and well-being of the person with dementia. A suite of three Government Acts frame this protective approach, based on a human rights perspective. These Acts are:

- Adults with Incapacity (Scotland) Act (2000)

- Adult Support and Protection (Scotland) Act 2007

- Mental Health (Care and Treatment) (Scotland) Act (2003)

All three of these Acts share common principles including:

- any response from others should be of benefit to the person.

- action taken by others should be the least restrictive possible.

- the approach taken should be person centred.

- the views of the person should be listened to and considered.

- the views of others who are closely involved should be listened to and considered.

If the person with dementia requires help in making decisions or planning, it is possible to grant another person, usually a family member, legal powers to make decisions for them. This can involve decisions about the person's financial and/or welfare needs and this may have an impact on their housing situation.

Any concerns about the wellbeing of the person can be brought to the attention of the Mental Welfare Commission for Scotland. The Commission protects the welfare of people with mental disorder, learning disability and dementia, no matter where they live. They can be contacted freely by any member of the public or professionals at http://www.mwcscot.org.uk/

Confidentiality and sharing information is crucial to improving the support for the person living with dementia and may include information sharing within family and friend networks, in addition to support services and other staff. External authorities are rarely asked to manage confidentiality within families unless there are legal implications. However, all professional practitioners are required to follow the guidance of their own professional codes of practice.

The process of early recognition and diagnosis of dementia advocated in Scottish legislation would allow the introduction of housing considerations at a point when the person is able to be fully involved in current and future planning. Early engagement may also contribute to anticipatory planning by the wider health and social care team. Being involved in decisions about the future as soon as practical can contribute to giving the person living with dementia more choice and control over future support and care needs (Joint Improvement team and NHS Scotland, 2016).

2.3 Support and training for housing staff

Staff working in housing join an increasing need for professionals in all disciplines to develop roles to support the person with dementia (van Hoof et al, 2010). Housing staff working within social housing are likely to have contact in the early stages with people who are living with dementia, whether the

Chapter 2
Living Well with Dementia

person has received a diagnosis or not. Those people who are owner occupiers or rent privately are only likely to make contact with services such as Care and Repair. Therefore these practitioners may have a key role for front line access and interventions.

Developing knowledge and skills about dementia is therefore important. The Scottish Government Joint Improvement Team commissioned the project 'Improving Housing and Housing Services for People with Dementia' in 2013. A survey carried out as part of this project aimed to assess levels of dementia awareness and identify training needs amongst housing staff in Scotland. The survey had 276 responses from a variety of housing organisations across Scotland. The majority (54%) worked for registered social landlords and there was even split across senior management, middle management and frontline staff. The key finding was a large variation in dementia knowledge and awareness in housing staff. The majority of the sample (83%) reported that they had come across a person affected by dementia within the course of their work. There was a high level of support (76%) for the role that housing staff could play in supporting people affected by dementia yet housing staff in the survey did raise concerns or problems they had experienced when working with people living with dementia, often around the person knowing or accepting they had a

diagnosis of dementia. The majority of the participants (72%) had never received training about dementia, however 74.3% said they would be interested as part of their role, in frontline staff, this percentage increased to 89%. (Joint Improvement Team and the Chartered Institute of Housing (JIT &CIH), 2013). This lack of understanding could constrain the impact of housing staff, who are beginning to play a role in local and strategic groups (JIT& CIH, 2013).

More recently, the Chartered Institute for Housing Scotland (CIH) has commissioned work to assess the training need of frontline housing staff in more detail. Commissioned from CIH Scotland from Arneil Johnston (2017) this survey found that 55% of front line housing staff lack confidence in what they know about dementia. Crucially almost 97% agreed that housing has a key role to play in supporting the person living with dementia.

Very little is known about the knowledge and awareness of the diverse group of people providing services to people living in owner occupied housing. Current initiatives to raise awareness, such as Dementia Friends, Dementia Friendly Communities and campaigning work by organisations such as Alzheimer Scotland may not as yet have suficient reach for this group of people.

While these reports point to a clear need to develop learning about dementia for

social care staff, information about others working in housing related occupations affecting social rented or owner occupied housing is not readily available.

Key findings

- Those who work within housing services, including practitioners, support and maintenance staff, identify gaps in their knowledge about how to support a person with dementia and their family.

- Very little is known about the knowledge and awareness of dementia among providers of housing related services in the private sector.

- Collaboration within health and social care integrated teams is not fully realised or inclusive of the housing contribution.

Chapter 3

Dementia and Housing: Policy Perspectives

Chapter 3
Dementia and Housing: Policy Perspectives

3.1 Dementia policy in Scotland

Scotland's policy context confirms ageing in place as a universally accepted ideal. Dementia strategies and policy have supported this concept together within a rights based approach. The Scottish Government has produced two national dementia strategies (Scottish Government 2010; 2013). Both are underpinned by a human rights approach and informed by the Charter of Rights for People with Dementia and their Carers in Scotland (2009). Each national strategy has provided a three-year plan to address priorities agreed through public and professional consultation. There is a third strategy to be published in 2017. While the content of this is not available at the time of this report, early discussions and dialogues held throughout Scotland have raised the topic and interest in this area. It is likely that this will be featured in the third strategy but the extent to which it will be prioritised is not known. However the continuing emphasis on early diagnosis and support in the community should encourage a greater focus on home and housing.

The first Scotland's National Dementia Strategy (2010-2013) primarily focused on: improving rates of diagnosis; enhancing assessment and diagnosis pathways; improving the experience of people with dementia and their families within acute care services; addressing the awareness, education and skill gaps of health and social care staff in all settings, and addressing issues around rights, dignity and stigma. While the role of housing could be significant in all of these aspects, specific directions are not explicitly outlined.

Two documents produced in 2011 continue to inform the direction of support provided to people with dementia: these are Standards of Care for Dementia in Scotland (Scottish Government, 2011a) and Promoting Excellence: A knowledge and skills framework (Scottish Government, 2011b). The framework is primarily for health and social care staff but also available to other professions working within dementia care which guides towards skills and knowledge that are required to be supportive to people with dementia at each point on the journey from earliest concerns to end of life. Levels range from a basic 'informed' status to 'expert'. These are available freely and intended as guidance by any practitioner who has contact with a person who has dementia. The extent to which housing has been engaged with these documents is not clear.

Three models are evolving, developed by Alzheimer Scotland, to direct services and provide continuity of support. These are the Five Pillar Model of Post-Diagnostic Support, the Eight Pillar Community Support Model and the

Advanced Dementia Practice Model at http://www.alzscot.org/campaigning/

All three of these models refer to housing issues. However these are short statements within all three models and more emphasis is needed to make the opportunities for a housing contribution more explicit.

The Five Pillar model frames support when the person receives a diagnosis of dementia. There is no explicit guidance about housing options or choices, instead a person centred, needs led approach to future planning is advised. A more proactive approach would reinforce early consideration of housing condition, safety and adaptations, including any moves to other accommodation. Housing adaptations and assistive technology are more clearly embedded in the Eight Pillar model; this is used where the person will need increasing help and support. Some mention is also made of extra care housing as being considered at this point in the person's journey. Within the Advanced Dementia Practice Model there is little consideration of housing issues. The current picture is that many people with advanced dementia are currently cared for in care homes or hospitals and generally the model may be perceived as supporting care provision rather than setting.

The second dementia strategy (Scottish Government, 2013a) has a greater focus on quality of life at home. Key objectives have been to see more people with

dementia living a good quality life at home for longer; dementia-enabled and dementia-friendly local communities; timely, accurate diagnosis; better post-diagnostic support; people with dementia and their families and carers as equal partners in care and greater respect and promotion of rights in all settings. An important outcome desired of the models being developed is that people with dementia remain at home for longer should they wish to do so. This is aligned with the National Health and Wellbeing Outcomes, particularly outcome two which supports independent life at home as far as is practical (The Scottish Government, 2015b).

The third dementia strategy is to be published in 2017, however, proposals have emerged from dialogue events held across the country. There is likely to be further promotion of technology-enabled care, equipment and adaptations. While the extent to which further housing concerns are included is not known as yet. It is proposed that one of the priority proposals in the draft Scotland National Dementia Strategy 2016-19 (Scottish Government, 2016a), includes working in collaboration with Integrated Joint Boards to support locality planning. One expectation should be the review of Scotland's Housing Strategy for Older People to consider the needs of people living with dementia.

Chapter 3
Dementia and Housing:
Policy Perspectives

3.2 Integration of health and social care

The changes underway towards integrated services are an effort to meet the population's diverse and changing needs. The person living with dementia may have needs generated by individual diseases, co-morbidity, degree of impairment, living arrangements and personal and relational concerns. Provision of support will need to not only meet the needs of individuals but also be changed and adapted as needed by the person and the carer. To address these challenges, including the ageing population in Scotland, the Public Bodies (Joint Working) (Scotland) Act (Crown Copyright, 2014d), set out the legal framework for integrating health and social care. A central aim of integration is to shift }the balance of care to the community setting, ensuring that resources can be better employed to meet the needs of the person.

Successful integration of health and social care is expected to provide the opportunity for more people to remain at home or in a homely setting. To support this both prevention and advance planning is needed to improve safety and reduce the need for unplanned moves to hospital or other care settings (The Scottish Government, 2015). To achieve the ideal of maintaining the person at home will require physical adaptations and the provision of assistive equipment including technology. The potential role of fire and rescue services in supporting the person to reduce domestic fire risk and falls risk, suggests further integration and partnership with more diverse agencies could also be fruitful (Lowton et al, 2010).

"Last year I nearly burned the house down because I had put the wrong ring on the cooker...my wallets on fire, all my cards, bank cards, library cards, everything was in there – melted. Talk about stress!"

Ian who lives with dementia (Sharp, 2016)

The integration of care will impact on family and carers, who play a vital role in the life of the person living with dementia and report a range of challenges in the current health and social care services. Brodaty et al (2005) found that lacking information about what might be available can impede carers. A study of carers' experiences where services were described as a 'maze', limited and lacking flexibility and engagement with services was reminiscent of a battle (Peel and Harding, 2013). Carers in this study found systems to be challenging and difficult, time consuming and arbitrary.

"There is so little information up front. There is no one to ask really, everything happens through the day and if you work it doesn't happen."

Elaine, family carer

The inclusion of housing as an Action Area by the Joint Improvement Team is a recognition of the important role for good quality housing and services, particularly for older people (Joint Improvement Team, 2015). Housing will be a key consideration in the shift in the balance of care that underpins the integrated and collaborative approach currently being implemented. As yet the move to full integration is not considered rapid enough to meet changing needs (Audit Scotland, 2016). However, there are a range of local and strategic plans in development.

POSITIVE APPROACH

A group of health, social care, including housing practitioners, in a North Lanarkshire Health and Social Care Partnership area meet six weekly to discuss issues affecting older people living in their catchment area who have long term conditions, including dementia. They are able to proactively address concerns raised by any of the group and find solutions together. This has led to anticipatory arrangements that allow better outcomes for the person and allow better planning for housing adaptations.

Chapter 3
Dementia and Housing: Policy Perspectives

3.3 Housing policy and strategy

It is clear that there are very few housing options or housing policies that are specifically focussed on providing accommodation for people with dementia in Scotland. For example, there are only three distinct references to dementia in Scottish Government's Strategy for Housing for Older People: 2012-2021. Where reference is made to dementia, housing and spatial planning policies, these cite dementia strategies and demographic data but rarely embrace specific policies for people with dementia. From discussions in preparing this report there is an expressed intention to develop new dementia specific policies within spatial planning and joint housing delivery plans but these have yet to be formally adopted and put into action. Given the current lack of published plans and reports, those relevant housing policies, particularly with an impact on older people, will be examined. This will include where older people live, types of housing, tenure and the physical condition of the property.

Much of this policy guidance is derived from the wider housing policy and standards related to older people, an area where the Scottish Government has made a long-term commitment. All Our Futures: planning for a Scotland with an ageing population (Scottish Government, 2007), presents an infrastructure of housing, transport and planning for the ageing population. Included is an increase in funding for care and repair services, integration of services and in particular the development of "all-age housing" suitable for the person's changing needs throughout life. The aim was to achieve a joined up approach with Local Authorities, businesses and voluntary services all playing a part. This would then inform local housing strategies and increase new options across all tenures, make use of new technology and provide a wider range of integrated support services. It is clear that this direction continues to inform policy and practice but the extent to which it has been achieved is less certain.

Homes Fit for the 21C, (Scottish Government, 2011c) sets out the Government's vision and strategy for housing until 2020. While no specific reference to the person with dementia is included, some observations are made on older people's housing. The strategy identifies a housing system for Scotland that caters for all in the provision of affordable housing. Specifically, provision of different types of dwelling to meet needs, including those of older people and those who have a disability. The strategy also makes reference to the condition and safety of buildings. There is an expectation for close working relationships between housing officials and community planning partnerships to enable appropriate good quality care and support for older people. Within

this context the strategy recognises the important role of specialist housing for older people, and services for care and repair and adaptations.

Subsequently, the Scottish Government published a series of action points in 2013 to report on progress. This document included Item 10: Homes that meet people's needs: Supported Independent Living, which included reference to older people and disabled people. The action points refer to the development of working groups and the creation of a national register of accessible housing for disabled people, which has been developed by Home2Fit (Glasgow Centre for Inclusive Living, ND).

The current over-arching policy in Scotland for older people is Age, Home and Community: A Strategy for Housing for Scotland's Older People: 2012 – 2021 (Scottish Government, 2011d). This recognises the value of ageing in place with a vision that 'older people in Scotland are valued as an asset, their voices are heard and older people are supported to enjoy full and positive lives in their own home or in a homely setting' (Scottish Government, 2011d:3). To support this vision, the framework includes balancing the housing provision across all tenures, including mainstream and specialist housing that can be adaptable to the needs of older people. Appropriate provision and support should encompass information and advice, adaptations

including telecare and promoting social networks. These are expected to support older people to remain in their own choice of home for longer (Scottish Government, 2011d), rather than in care home or hospital settings (COSLA and the Scottish Government, 2010). This reflects the wider UK vision of care that is both personalised and of high quality, requiring innovation in the incorporation of new technologies into homes. (Department of Health, 2015). While there are some references to dementia within the strategy document these are limited to cross references to the Dementia Strategy and a Case Study on Extra Care Housing. The Housing Strategy document recognises the role for Housing for people with dementia and refers to adaptations and re-ablement for people returning to their home following hospital discharge. This is about to be refreshed and updated.

There is also support for public investment in sheltered and very sheltered housing, to provide an alternative accommodation to care homes and reduce the level of emergency hospital admissions. The strategy suggests that there are around 6% of people over the age of 65 living in housing with care within Scotland. According to Census 2011 data there are 890,334 people over the age of 65 in Scotland. It is also estimated that there are around 53,000 people living in housing with care in Scotland (National Records of Scotland, 2014). This is broadly in line with Scottish Government

Chapter 3
Dementia and Housing:
Policy Perspectives

data on the supply of sheltered and very sheltered housing and medium dependency dwellings. The Strategy recognises that the majority of this form of housing is within the social housing sector although it does suggest that private provision has 'increased in popularity'.

It is not possible to verify the increase in private provision for supported housing, as such data is not available. However, the principal developer of older people's housing, McCarthy & Stone, is proposing to build 940 apartments over the course of the next five years which is less than 200 apartments per annum. Given that the company have around three quarters of the market share it is not expected

> There are very few housing options or housing policies that are specifically focussed on providing accommodation for people with dementia in Scotland.

that older people's private housing will exceed 300 dwellings per annum. This represents only around 2% of the total annual new build production and less than 10% of the total supply of specialist housing for older people in Scotland. Given that 73% of older people live in owner occupied housing this suggests that the supply of older people's housing is inadequately balanced with the needs of older people. There is little private provision for older people provided by other companies. This makes provision vulnerable to the operations of a single private supplier who can determine the quantity of supply based on their own commercial judgements. The Scottish Government has to re-shape supply by having policies that stimulate wider provision.

The Wider Planning for an Ageing Population report (Scottish Government and Cosla, 2010) produced two outcomes relevant to this discussion. Outcome 3 states 'Investment in new housing provision across the sectors meets future needs of older people' and indicates new build development only meets the needs of a small proportion of older people but recognises that it could make a greater contribution. Despite stating the aim to ensure that the private sector should contribute to housing for older people there is no indication how the private sector could be motivated, or even regulated, into providing more housing for older people and the market stays focused on

family housing which has the benefit of purchasers who hold reasonable levels of equity assets. Despite an increasingly ageing population, there has been a lack of participation in the retirement housing development market in Scotland, including homes specifically designed for people with dementia. There is often a limited period where the person living with dementia can find it easier to move home or adapt. At some point in the person's expereicne of dementia this opportunity can be lost Therefore having limited housing options across tenures and any delay in putting equipment and adapations in place can lead to a missed opportunity to maintain the person at home.

Outcome 5 states 'The infrastructure to support these outcomes is improved', and includes the provision of more information and advice and more effective assessment and analysis of housing needs particularly for those people with dementia. Working with other organisations the objectives of Home2Fit pilot work is to provide greater levels of information and advice working with other organisations. The Integration Authorities and local authority housing services will be responsible for preparing their own housing strategies including strategic housing investment plans that are also aligned with work undertaken by local planning authorities in their Housing Needs and Demand Assessments.

Scotland's Sustainable Housing Strategy (Scottish Government, 2013b) provides

a significant range of Scottish Government policy documentation on housing standards including Quality Housing Standards that acts as a benchmark of quality for social housing and Scotland's Sustainable Housing Strategy. It is recognised by Scottish Government that there are many dwellings, particularly owner occupied and private rented accommodation, in Scotland that are in some form of disrepair and have poor energy ratings. From the data, which is outlined in the chapter below in the Housing Condition section, we know that a significant number of sub-standard dwellings are occupied by older people. Various policy and funding initiatives have been attempted to improve the stock including adaptations, Help to Buy and other Loan schemes. The sustainable housing policies seek to address, general housing standards, fuel poverty issues, requirements for people who are old or have disabilities and more broader climatic change targets with an Energy Efficiency Programme.

The Joint Housing Delivery Plan (JHDP) (Scottish Government, 2015a) is a plan across the whole Scottish Housing System. The Plan is subdivided into various sections with the relevant sections for older people housing but there are no specific references to dementia. Action 22 recognises the shortfall in provision of older people's housing by highlighting that the need for more options to support care needs and provide choice. The intended outcome

Chapter 3
Dementia and Housing: Policy Perspectives

is older people moving to suitable accommodation where they can be supported into older age. This will also facilitate release of larger, potential family homes into the public and private sector supply.

3.4 Spatial planning policies

The Scottish Government's Scottish Planning Policy (SPP), 2014a provides a national framework for land use spatial planning policy and the Scottish Minister's planning priorities for the development and use of that land. This policy is designed to provide policy consistency across Scotland in developing and maintaining local development plans, the design of projects, planning applications and decisions.

Scottish Planning Policy states that a five year supply of effective housing land should be maintained at all times. This five year supply of housing land should be informed by a Housing Need and Demand Assessment (HNDA) which considers 'the need for specialist provision that covers accessible and adapted housing, wheelchair housing and supported accommodation, including care homes and sheltered housing. This supports independent living for elderly people and those with a disability. Where a need is identified, planning

authorities should prepare policies to support the delivery of appropriate housing and consider allocating specific sites' (Scottish Government, 2014a).

The Housing Need and Demand Assessments (HDNA) should include a detailed survey and analysis of older people, their housing tenure, projections on older population through and beyond the period of the development plan and a breakdown of older people's disabilities including those with dementia.

This highlights the significant overlapping and inter-department working that is required from Social Care, Housing and Spatial Planning to identify and plan for the housing requirements for people with dementia. Further collaboration will now be required through the duties of the Health and Social Care Partnership.

The compilation of data that contributed to the HNDA was also assisted by Alzheimer Scotland. It will be critical that local authorities, Health and Social Care partnerships and third sector organisations work together in the sharing and analysis of data and development of policy and practice for people with dementia and their accommodation requirements.

Unfortunately, while having noted some references to dementia in Scottish HNDAs, there are no identified, specific spatial planning policies relating to dementia within local development

plans. Additionally, the evidence shows little material increase in the supply of 'specialist provision' referred to within the SPP.

Planning Use Categories

Spatial planning is sometimes referred to as 'land use planning' which essentially highlights that most land is categorised by its use. Where a building or land is used for a particular purpose it will or should be included for planning purposes within a 'use class'. There are eleven types of use class set out in the Town and Country Planning (Use Classes) (Scotland) Order 1997. Where there is a change of use between one class to another there is normally a need to obtain planning consent.

Spatial Planning defines Care Homes as a 'residential institution' (Class 8 Residential Institutions). It is also worthy of note that the Order (a statutory document) refers to a 'nursing home' whereas it could also be a residential care home or any building that provides care where people live together. In the event of Extra Care the planners may recognise this as independent living (Class 9 Houses) but may still need to separately categorise associated buildings such as office / care day room / kitchens. Alternatively for planning purposes Extra Care Housing may be deemed to be under Class 8 rather than a residential dwelling.

The Use Class order of 1997 highlights

that a 20 year old order does not quite correlate with care service practice and certainly referring to a care home as an 'institution' has rather negative connotations when it is considered to be the person's home.

Place Making Agenda

Over the course of the last 15 years the Scottish Government has been developing policies to support an objective of designing better places. While policies were initially focussed on physical design, particularly new housing design, there has been an increasing recognition that good 'place making' is about the inter-relationship of physical and social aspects including the importance of connectivity.

This inter-relationship was further developed through co-operation of Scottish Government, NHS Scotland and Architecture and Design Scotland's with the publication in 2016 of the 'Place Standard' which is a methodology that helps people to evaluate the quality of their place whether it is an existing place or one that is to be re-developed or further planned. Using the 'Place Standard' tool, an evaluation should be undertaken to assess how older people and those with dementia see their place and what actions that can be taken to improve their environment, support and service.

https://blogs.gov.scot/planning-architecture/tag/place-standard-tool/

Chapter 3
Dementia and Housing:
Policy Perspectives

POSITIVE APPROACH

Plymouth has issued a policy statement that it wants to 'become a Dementia Friendly City, recognising the influence of the modifiable risk factors and the great diversity among individuals with dementia and their carers. The 'Plymouth Plan' highlights a need to promote a healthy city. Specifically the Plan indicates that a key identified need is 'to make Plymouth into a more dementia friendly city, enabling people with dementia to be able to live as normal a life as possible by ensuring that their needs are considered in all walks of life.

http://plymouth.objective.co.uk/portal/planning/ldf/plymouth_plan/pptp_health_wellbeing?pointId=d205126e2256

The Plymouth spatial plan recognises that there are benefits from arts, heritage and cultural activities that form part of a 'suite of tools that reduces the impact of mild to moderate dementia'. The Plan reports that its ageing population and dementia is 'becoming increasingly more common and generating significant emotional, social, and financial costs to the person, family, community, and wider society'. The spatial plan acknowledges the importance of early diagnosis and providing support to people and their carers.

It will also promote the inclusion of people living with dementia in all areas of community life, respecting their decisions and lifestyle choice, anticipating and responding flexibly to their dementia related needs and preferences.' By identifying the links between dementia, the built environment, services and activities, the local planning authority working with its public partners and community bodies have demonstrated an understanding that planning policy does indeed have an impact on people with dementia along with their care support.

Further emphasis on connecting people with places is emphasised in the Scottish Planning Policy, (Scottish Government, 2014a), with the following statement: 'Improved connections facilitate accessibility within and between places – within Scotland and beyond – and support economic growth and an inclusive society'. The involvement and contribution of local community based organisations as part of the spatial development plan process was identified as an important issue in the recent Scottish Planning Review (2015a).
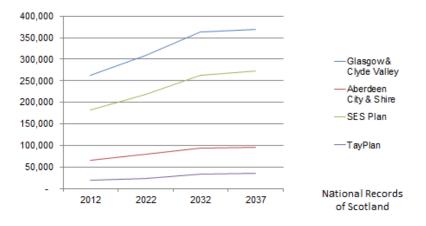
In recognition of the role that is required from spatial planners, the Royal Town Planning Institute (RTPI), the professional institute for spatial planners, has provided new advice outlining to professional planners the growing prevalence of dementia and built environment issues that impact on people with dementia including the need to plan for adequate effective housing provision (Royal Town Planning Institute (RTPI), 2017)

Scottish Spatial Planning includes four 'strategic development plans' that inform local spatial development plans on such matters as housing land supply. These four strategic plans are organised by strategic planning authorities based around Scotland's four main urban conurbations:

• Aberdeen City and Shire

• Glasgow and Clyde Valley

• Edinburgh and South East Scotland – SES Plan

• Tayplan – Tay cities region (Fife, Dundee, Angus and Perth & Kinross

The following graph highlights the growth in projections for the population of those aged over 60 years.

Household Projections for those aged 60 and over within Strategic Development Plan Areas

National Records of Scotland

Chapter 3
Dementia and Housing:
Policy Perspectives

The above graph highlights that the ageing population grows at a relatively greater rate in the metropolitan regions of Edinburgh and Glasgow. While the strategic planning authorities have recognised the growth in the population of older people there is a shortfall in subsequent spatial planning policies to reflect such a growth and the impact of an increase in people with dementia. The RTPI does recognise that spatial planners have an important role in devising built environment policies that correlate with health and social policy requirements but this has yet to be fully developed into plans and action.

3.5 Community empowerment

In 2015, the Scottish Parliament enacted the Community Empowerment (Scotland) Act, with the intention that this legislation provides a statutory basis for community planning and for empowering communities through the ownership of assets and communities having a greater say in shaping their future. The Scottish Government is seeking through its Community Empowerment legislation and policies to improve community outcomes by bringing together local service providers with the intention that this is led by the Community Planning Partnerships. This is expected to lead to a greater level of 'co-production' in

developing solutions with an integration of what the people in the community want with those being provided by the public service organisation. East Ayrshire Council through its 'Vibrant Communities' initiative is a leading Scottish local authority that is seeking a greater level of co-production between Council departments and community organisations through the production of community led action plans. While these plans should include the requirements of older people and those with dementia, however currently many of the community priorities tend to be related to short term projects rather than addressing more medium to longer term strategic investment decisions. The matter of who should be consulted in development planning is vague. There is no reference to statutory consultees in Development Plan Circular (6) 2013. However, it is generally recognised that community councils are 'key stakeholders'.

3.6 Ageing in place with dementia

"…as I've understood it - this illness - you be as normal as you can be for as long as you can, right?"

Susan who lives with dementia (Sharp, 2016)

In Scotland, as elsewhere, it is acknowledged that, whenever possible, most people would choose to age in place (World Health Organization, 2007). That is, to continue to live in their chosen home or within their own community as they grow older (Scottish Government, 2011a). 'Place' in this context is a broad concept that goes beyond the physical surroundings of the home and includes what is meaningful and important to the individual about their surroundings (Chippendale and Bear-Lehman, 2010). It is people and their interaction that define places and therefore community and place are inevitably inter-linked.

The UN Convention for Rights of Persons with Disabilities, Article 19 recognises the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community. Quality housing in the right place with good connections has been recognised as playing an essential role in a person's involvement in the places beyond the home. This involvement is vital to maintaining quality of life by facilitating access to the local community and its services (World Health Organization, 2007).

When an older person is ageing with a dementia diagnosis 'ageing in place' is typically the preferred choice, and many benefits have been recognised for remaining in a familiar environment (Gabriel et al, 2015). That said, for many people with dementia and their caregivers, relocation to live away from the current home might become a necessity for multiple reasons (Chippendale and Bear-Lehman, 2010). These reasons are often similar for all older people and include concerns with financial, health and functional status (Ewen et al, 2014; McFadden and Lucio, 2014)

"I would like her to have stayed at home but she was going out in the street at all times and the only option I was given was to stop work and look after her. No one offered an assessment."

Elaine, family carer

It has been noted that throughout the housing policy documentation that reference to dementia is minimal, although there are significant references to people who have a disability. A key question arises as to whether under the terms of legislation and policy, dementia is deemed as a disability. Under the Equality Act 2010 a person is disabled if they have a substantial or long term condition that adversely impacts their daily living. Such terms are defined within the legislation as a physical or mental impairment that

Chapter 3
Dementia and Housing: Policy Perspectives

has a substantial and long-term adverse effect on a person's ability to carry out normal day to day activities. Long term usually means a condition or impairment that will endure (or is expected to) for 12 months or more. The exception is for progressive conditions where the definition applies from the date of diagnosis. Dementia is clearly a progressive condition and will, more often than not, have a long term adverse effect on an individual. Social housing practitioners suggest that while one can rely on the requirement to "make reasonable adjustments to service" arising from the equalities legislation, housing guidance on adaptations should be updated to reflect such matters.

Currently The Chronically Sick and Disabled Persons Act (Scotland) 1970 is still active and is the basis for the duties to assess someone with a disability and to make arrangements to provide support, including adaptations. This legislation reflects the duty of assessment but does not specify dementia. The current Adapting for Change improvement programme continues to refer to older people and disabled people (Scotland's Housing Network, 2017). The inclusion of people with dementia may be implied within these groups but this is not specified.

Key findings

- Distinct and independent policies and guidance are available in Scotland about housing and dementia. These state the importance of each topic, but all lack detail about what should be done.

- Housing and planning guidance contains some consideration about meeting the needs of an ageing population, but few reference people living with dementia.

- Currently, people living with dementia and their family lack information about general housing advice, support and funding.

Chapter 4

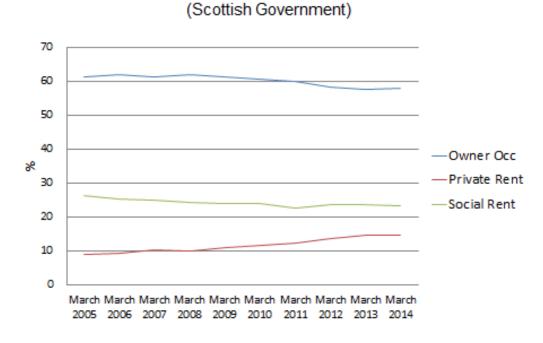## Current Housing Options

Chapter 4
Current Housing Options

4.1 Housing tenure

There are three main tenures, Owner Occupation, Private Rented Sector and the Social Rented Housing Sector. Both the private rented and social rented tenures comprise of occupying tenants who pay a rental to a landlord. Rental levels in the private sector are largely established by the market whereas the social rented sector rental levels are established by the policies of the registered social landlord. 'Affordable Housing' is not a tenure per se but housing that is defined as being affordable that could be rental or owner occupation or a shared ownership/equity arrangements. Social housing rents are set by landlords and there has to be a balance between having sufficient income to cover costs with a level that tenants and the welfare system can meet. There is no housing data available about people who have been diagnosed with dementia and older people's housing data is largely limited to social housing through either local authorities or housing associations.

Owner occupied housing is the most common tenure type in Scotland in 2009, owner occupation represented 61.4% of total stock but this fell to 58% in 2014 (Scottish Government 2016c). The availability and access to social rented

Scottish Housing Tenure 2005-2014
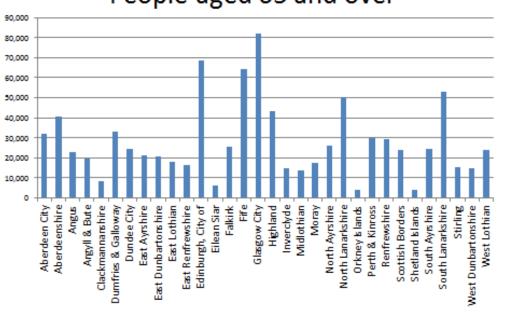### (Scottish Government)

housing has decreased in recent years and currently accounts for 23.5% of total stock. Conversely, the private rented market has continued to grow over the last decade and by 2014 the private rented sector represented 14.8% of total stock in Scotland with the Scottish metropolitan cities having significantly higher levels than the national average.

Housing Tenure for Older People

Census 2011 data indicates that there are 890,334 people aged 65 or above in Scotland representing 17% of the Scottish population. The Census 2011 data also highlights that there are

230,428 people aged 80 or above in Scotland representing 4.4% of the total Scottish population. The number of older people living in Scotland varies across local authority districts are shown in the graph below.

Older People Living Alone

According to Census 2011 data the proportion of single person households aged 65 years or over tend to live in more rural locations. In East Renfrewshire 53% of all single households comprise of people aged 65 or over whereas the Scottish average of single households is 41%. While the metropolitan cities

Scottish Population Distribution of People aged 65 and over
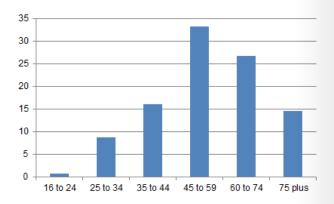
Chapter 4
Current Housing Options

of Glasgow and Edinburgh have lower proportions of older single households the number of older people living alone in these cities is still high with 38,746 people aged 65 or over living alone in Glasgow and 26,627 living in Edinburgh.
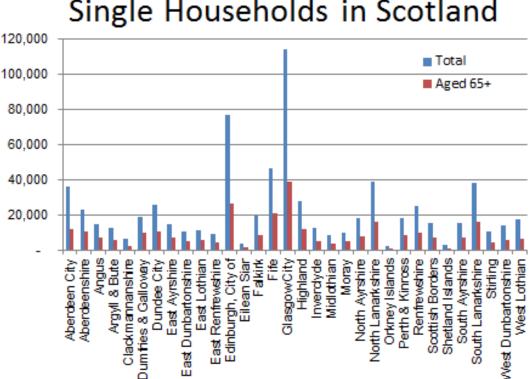
Older People Living in Owner Occupied Housing

According to the Scottish Household Survey Annual Report (2016e), 41% of all Scottish households in owner occupied housing are aged 60 or over. This graph highlights that people of retirement age dominate the owner

occupied sector with some 73% of head of households aged 60 or over living in owner occupied housing.

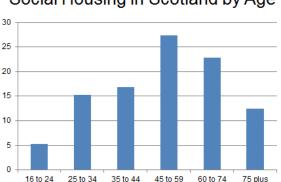**Percentage of Households in Owner Occupation in Scotland by Age**

Single Households in Scotland
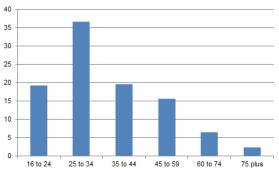
Older People Living in Social Housing

This graph indicates that there are some 35% of all social tenants aged 60 years or over.

Percentage of Households in Social Housing in Scotland by Age

Older People Living in the Private Rented Sector

This graph highlights that 7% of tenants aged 60 years or over live in private rented accommodation.

Percentage of Households in Private Rent in Scotland by Age

Given the demographic data a significant majority of older people live in owner occupied dwellings. While in general the proportion of people living in owner occupied accommodation has declined since the recession, such a decline is less likely to include people of an older age. The distribution of the older age population is proportionately greater in more rural locations in Scotland. Also, there are an estimated 296,136 (41%) of older people living on their own in Scotland.

Provision of Sheltered & Retirement Housing

Sheltered housing is designed specifically to support the needs of older people. Some of these facilities are supported and managed by either a full or part time scheme manager. Private housing for sale is usually defined as 'Retirement Housing' but the facilities and building form are usually similar.

The Scottish Government's House Key website identifies that there is a total of 2,013 Scottish housing facilities for older people of which 144 facilities for purchasing accommodation. Therefore, only 7% of the total accommodation is designed and operated for older people is for purchase. This very small proportion of older people's housing supply highlights that even allowing for some people to transfer from owner occupation into social housing, there is an inevitable shortage of such accommodation given

Chapter 4
Current Housing Options

that 73% of all older people live in owner occupied housing and evidence suggests that 58% of people aged over 60 years were interested in moving (Wood, 2013).

The charity, First Stop Advisory Service, (2015) highlighted in the period April – September 2015 that 38% of their enquiries came from people who were wanting to move house. A further 8% said this was their second reason for making an enquiry. However out of those people who made enquiries that did move, only 10% moved into private facilities compared to 44% moving into social sector facilities. A number of people making enquiries to First Stop (England) believed that moving house was their only option but when they were informed of other options that allowed them to stay in their own home around 50% decided to stay where they currently live. While some people moved between owner occupation and sheltered social housing, this was limited due to the asset wealth of the owner occupier. Anecdotal data from Alzheimer Scotland helpline suggests that more younger people are likely to phone in relation to housing. Questions related to older people are more likely to be related to sheltered or supported housing.

Scottish Housing for Older People

The Scottish Household Survey provides data on the different types of accommodation provided for older people by local authorities and housing associations. The data is incomplete

with some information not provided by some local authorities. Additionally, housing association data is only provided up to until 2013 whereas local authority data is provided up to 2015. Therefore this report provides data up to 2013 in an attempt to gain a fuller picture of provision.

As a comparison figure, the number of older people in sheltered and very

Older People's Housing in Scotland by Local Authorities & Housing Associations 2013
(Scottish Government 2016)

	2013
Sheltered Housing	31,204
Dwellings with community alarm (LA only)	27,093
Housing for Older People Medium Dependency	15,034
Very Sheltered Housing	5,482
Housing for Wheel Chair Adapted (LA only)	2,131

sheltered housing is broadly the same as residents in Care Homes (34,738 in 2016). Various research has estimated that between 69 and 80% of residents in care homes are living with dementia (Alzheimer's Society, 2014b; Lithgow, Jackson and Browne, 2012; Whelan et al 2013). We do not know how many people with dementia live in sheltered and very sheltered accommodation. However, some 9% of care home residents were discharged to supported accommodation in 2014 (Information Services Division (ISD), 2014).

Very Sheltered Housing

This is a form of housing, which can include extra care housing that provides the same facilities as sheltered housing but has additional elements for care support including equipment and services. According to Housing Statistics Scotland, in 2005 there were 3,893 very sheltered dwellings in Scotland, this has increased by 40% to 5,482 in 2013.

Sheltered Housing

This is accommodation designed to meet the needs of older people which will generally include level accessibility including lifts to upper floors, handrails, accessible temperature controls and electricity switches and sockets. Both sheltered and very sheltered accommodation may also have communal spaces for social interaction. As a result of housing policy and investment decisions the supply of social sheltered housing dwellings has declined over the last 10 years. In 2005 there were 33,212 sheltered dwellings in

Older People's Housing in Scotland by Local Authorities & Housing Associations 2004-2013
(Scottish Government 2016)

Chapter 4
Current Housing Options

Scotland compared to 31,204 dwellings in 2013. Some of the decline in stock is likely to be as a result of stock conversion from sheltered to other older person's accommodation categories such as very sheltered.

Sheltered Wheelchair Housing

This accommodation is designed to meet wheelchair standards and meet other requirements for older people's accommodation. It should be noted that the data is also included in the sheltered and very sheltered data, which effectively creates a double count in the provision. The data for wheelchair housing is only available from local authorities. The data shows an increasing trend albeit subject to annual variation. The fact that this data also features within sheltered and very sheltered accommodation makes it difficult to analyse, particularly when improvement programmes may bring about a change in housing category. However, in terms of the overall local authority investment in sheltered, very sheltered and wheelchair adapted accommodation there has been a small increase in provision over the last 10 years.

Medium Dependency / Amenity Housing

The accommodation is designed to meet the same standards as general needs social housing with additional specification elements to support the occupier's accessibility and safety within the dwelling. This form of accommodation has risen over the last 10 years. This increase to a certain extent reflects the policy strategy of independent living and is likely to be a cheaper method of new build housing than a sheltered provision. The provision of private tenures (rental and owner occupied) suitable for people living with dementia will only really be improved if planning policy and practice changes through better spatial and land use provision.

Summary of Older People's Housing Provision

The data available highlights that there is an uneven provision of older people's housing in Scotland and shows some increases in very sheltered and medium dependency housing for older people provided by housing associations. The provision of older people's housing by local authorities and housing associations has seen little change over the last 10 years. It should be noted that some of the stock might have been transferred from local authorities to housing associations during this period. The data also highlights that there has been a reduction of sheltered housing by local authorities over the last 10 or so years.
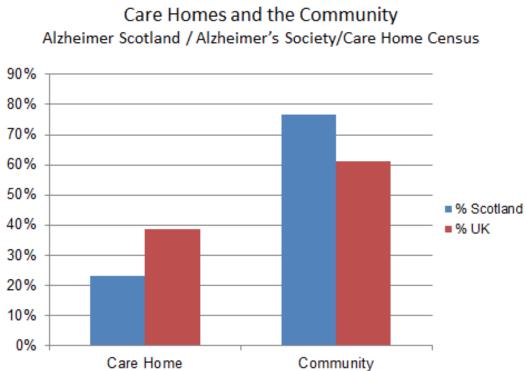
4.2 Housing provision for people with dementia

Using data from Information Services Division (ISD)'s Care Home Census (2013) Alzheimer Scotland/University of St Andrews and Alzheimer's Society highlights that there are differences between the proportions of people with dementia living in care homes and the community in Scotland compared with the UK as a whole. In Scotland it is estimated that there are around three quarters of people (66,000) with dementia (diagnosed and without a diagnosis) living in the community. This compares with 61% in the UK.

There are in total 296,136 single households over the age of 65 (Census 2011) representing a third of Scotland's population of people aged 65 years or over. Therefore, extrapolating the data it is reasonable to assume that there are over 20,000 people living on their own with dementia in Scotland.

The Housing Dementia Research Consortium Report (Barrett, 2012) highlighted that there were very few specialist housing provision for people with dementia. The report's findings were that housing with care

Estimated Percentage of People with Dementia Living in Care Homes and the Community
Alzheimer Scotland / Alzheimer's Society/Care Home Census

Chapter 4
Current Housing Options

accommodation is better suited to people at the early stage of dementia and less likely to be suitable for people with advanced dementia. The report also refers to research conducted by Housing 21 and Hanover Housing Association, which suggested around 25% of residents within Housing with Care accommodation had dementia. Work done by the Housing Dementia Research Consortium estimated that there were 2,384 residents with dementia within 246 Housing with Care schemes.

The Housing Options for People with Dementia report by Dementia Care (2015) identifies that while there is good design guidance for housing suitable for people with dementia, there is a lack of research into the models of new housing for those with dementia. The report outlines four emerging models for people living with dementia:

- Small, shared housing schemes, where residents have their own room but share communal facilities.

- Small assisted living schemes, where residents have their own self-contained accommodation (i.e. their own front door) with some communal areas.

- Extra-care housing where parts of the scheme are designated for people with dementia.

- Close care housing, comprising self-contained housing units (usually flats or bungalows) built in the grounds of a residential care home or nursing care home.

However, currently it is unclear to what extent older people and people with dementia are having their housing needs met within their current accommodation. As the data above has shown, owner-occupied tenure dominates the housing stock in Scotland and the proportion of owner occupiers that are of a retirement age is even significantly greater than the overall average owner occupation. However, older people's accommodation is focussed towards social housing although there are various Scottish Government schemes in place to help owner occupiers to adapt and improve their property to meet their needs. There are very few specific references to dementia in housing or spatial planning policies and the supply of housing designed for people with dementia is very small.

While there is enthusiasm for innovation in housing and dementia design, limited resources may be challenge to provision. There are a range of demonstration sites and new design ideas in the UK and beyond.

CROFTSPAR, SPRINGBOIG AVENUE, GLASGOW

The Housing Care website provides a search facility for accommodation for older people. Only one facility specifically catered for people with dementia. Croftspar is a partnership project operated by Alzheimer Scotland with the property being owned by Cube Housing Association. This facility described as 'enhanced sheltered' provides 8 one bedroom bungalows with on site extra care being provided. The other 14 facilities identified on the Housing Care website were sheltered offering non specific support for older people.

Chapter 4
Current Housing Options

BRE Innovation Park hosts a dementia friendly demonstration home at Ravenscraig near Motherwell. This retrofit flat includes a range of design and innovative technological solutions. Visitors are encouraged to comment on the environment and learn from the experience.

"We are continually looking for innovative design, technologies and systems which will inform the future of our built environment. With housing as a cornerstone of our communities, it is imperative that we continually look for innovative solutions that allow people to age well within their homes"

Dr. David Kelly Group Director BRE.

https://www.bre.co.uk/scotland/page.jsp?id=3747

Viewpoint Housing Association have created two dementia friendly flats to illustrate a range of design features, supported by Stirling University Dementia Services Development Centre (DSDC). Visiting these flats allow current and prospective tenents to explore how design might influence their daily life.
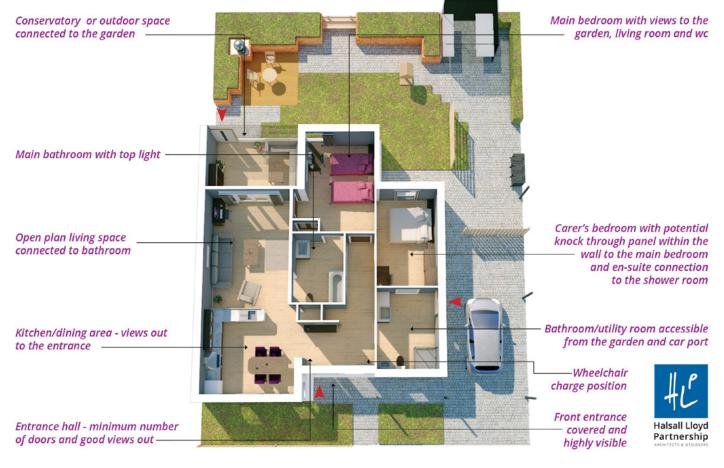

Viewpoint has produced an organisational strategy for dementia, including provision for staff training, provision of information and the creation of 'dementia friendly' and enabling environments (Viewpoint, 2016)

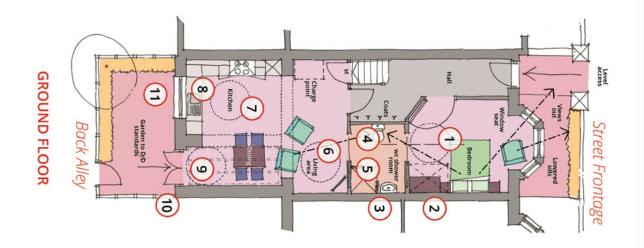http://www.viewpoint.org.uk/news/dementia-showflats

The 'Design for Dementia' Bungalow is a research project by Bill Halsall of Halsall Lloyd Partnership in-conjunction with Dr. Rob MacDonald of Liverpool John Moores University. This developed a design that may address some of the key issues that contribute to living well with dementia and could continue to support the person and family as it progresses.

DESIGN *for* DEMENTIA HOME

Conservatory or outdoor space connected to the garden

Main bedroom with views to the garden, living room and wc

Main bathroom with top light

Open plan living space connected to bathroom

Carer's bedroom with potential knock through panel within the wall to the main bedroom and en-suite connection to the shower room

Kitchen/dining area - views out to the entrance

Bathroom/utility room accessible from the garden and car port

Wheelchair charge position

Front entrance covered and highly visible

Entrance hall - minimum number of doors and good views out

Halsall Lloyd Partnership
ARCHITECTS & DESIGNERS

These design principles can be applied to a range of types of scheme including extra care and specialist residential care schemes or applied to retrofit of existing dwellings such as the Victorian Terraced House design below.

Chapter 4
Current Housing Options

GROUND FLOOR

Back Alley · Street Frontage

Garden to D/D standards · Kitchen · Dining · Living area · Charge point · Coats · St · Hall · wc shower room · Bedroom · Window seat · Views out · Lowered sills · Level access

1. hoist position
2. knock through panel in floor for possible future lift
3. bathroom to disability standards
4. wc and wet room - visible from bed position and living area
5. walk in shower
6. continuous floor - equal light reflectance value (LRV)
7. kitchen/dining area, open plan
8. kitchen with open shelving and glazed door/cupboard fronts
9. glass roof side extension - admitting natural daylight to open plan, living/dining/kitchen area
10. access to garden with level access
11. raised planting beds

⊙ wheelchair turning

FIRST FLOOR

First floor living area · Bedroom · Bathroom

SECOND FLOOR/ATTIC

Bedroom · Bedroom · Bathroom

Adaptation of a Traditional Victorian House

With thanks to Bill Halsall of the Halsall Lloyd Partnership and Dr. Rob MacDonald of Liverpool John Moores University. (Copyright Halsall Lloyd LLP) Available http://www.hlpdesign.com/images/case_studies/Vol1.pdf

The Hogewyck development near Amsterdam is called a dementia village and is a diverse urban setting with blocks of housing that reflect different living conditions where residents may have spent their life. This concept is built on the principle that that long term memory of spatial environments can support the person who moves to the village. Each block is different and reflects the range of lifestyles that the older population may have experienced. The concept of the dementia village has begun to expand from the original development at Hogeweyk to Switzerland and Italy.

- Dementia Village Amsterdam http://hogeweyk.dementiavillage.com/en/I

- Dementia Village Rome http://www.dementiavillage.com

- Switzerland village based on 1950's design https://www.youtube.com/watch?v=72zrqv74R0w

In Japan the Tsudoi-ba, or open house, is an initiative which depends upon access to relatively inexpensive, empty houses. These are used by members of the local community to provide a base to offer emotional support, company and meals for people with dementia and carers.

http://www.housinglin.org.uk/_library/Resources/Housing/Practice_examples/Housing_LIN_case_studies/HLIN_CaseStudy_105_Japan-Grassroots.pdf

In Australia the Transition Care Program (TCP) is a joint Commonwealth-State initiative that provides short-term restorative care for older people after a hospital stay. This period of 7-12 weeks allows time for decision making about their longer term care options. http://www.amanaliving.com.au/dementia-care/dementia-transition-care

4.3 House condition: risk and dementia

A person who is living with dementia may be less aware of their dwelling condition or any planned or reactive maintenance that is required. A major consideration is for an occupier to be comfortable within a home that is affordable to maintain and keep warm. The Scottish Government's Scottish House Condition Survey, in addition to providing an insight into information on housing conditions also provides data by age group. As can be found in other data sets there is no specific reference to information on the housing circumstances of people who are living with dementia. However, there are some key concerns raised around the management of risk and safety for older people and those with dementia.

- The age, form and type of housing

- The accessibility of housing in and around the dwelling

Chapter 4
Current Housing Options

- General condition of housing that could impact on the occupier's health

- The dwelling's energy and thermal efficiency and the risk of fuel poverty

In Scotland nearly two thirds of stock (63%) are houses and 37% are flats. However, in Glasgow three quarters of all housing stock are flats. According to Scottish House Condition Survey 2012-14, 31% of people in Scotland who are of a retirement age live in flats rising to 72% in Glasgow, 54% in Edinburgh and 48% in Dunbartonshire. This high proportion of retired people in urban and older flats will inevitably create access risks such as the lack of lift access in older tenement and other flatted accommodation.

In terms of the condition of the dwellings, the Scottish House Condition Survey data shows that 74% of people of a retirement age live in housing that is regarded as having some level of disrepair. The proportion of disrepair in housing occupied by older people is higher in East Ayrshire (93%), Angus and West Dunbartonshire (85%), Dundee and Stirling (84%), East Dunbartonshire and Scottish Borders (83%), East Lothian, East Renfrewshire, Edinburgh and North Ayrshire (81%) and Clackmannanshire (80%). Just over half of occupiers (54%) live in housing that is defined as having 'critical elements of disrepair' with around a third of people of

retirement age living in housing that has 'urgent disrepair'.

The Housing Condition Survey also assesses the safety of housing and their standard of quality. According to the survey an average of 13% of houses that are occupied by people of a retirement age are deemed to be unhealthy, unsafe and unsecure. However, this rises to 27% in Edinburgh and North Lanarkshire, 23% in Argyll & Bute and 22% in South Lanarkshire. Around half of dwellings occupied by people of retirement age are deemed as below the 'Scottish Housing Quality Standard'. This failure to meet such standards is more prevalent in some rural parts of Scotland (Shetland Islands 73%, Highlands and Western Isles 66%, Orkney 65% and Argyll & Bute 64%). Those people in rural housing can also be limited in their choice of energy with no-one living in the Northern Islands having a gas supply and only 12% having gas connections in the Western Islands. Even in the Highlands (63%) and Argyll & Bute (44%) there is a significant number without the benefit of a gas supply.

In summary, globally 'ageing in place' is a universally accepted ideal. Scotland's policy context supports this approach. However, it is unclear as to what extent older people and people with dementia are having their housing needs met within their current accommodation. As the data above has shown, owner-occupied tenure dominates the housing

stock in Scotland and the proportion of owner occupiers that are of a retirement age is significantly greater than the overall average owner occupation. However, older people's accommodation is focused towards social housing although there are various Scottish Government schemes in place to help owner occupiers to adapt and improve their property to meet their needs. There are very few specific references to dementia in housing or spatial planning policies and the supply of housing designed for people with dementia is very small. There are innovations in design nationally and beyond but these are sporadic and not evaluated in terms of effectiveness.

Key findings

- A higher proportion of Scotland's older people live in owner occupied than in social housing.

- There is concern that much of this stock has high levels of disrepair and poor energy efficiency.

- There is a dearth of accommodation appropriate to the diverse needs of people with dementia.

- Planning and building regulations currently do not support development of housing and services to meet the needs of the ageing population and in particular people living with dementia.

- There are numerous examples of good practice in housing and dementia, in Scotland and further afield, that could be implemented and developed.

- Housing associations lead in the development of innovative approaches, but this could be more effectively disseminated and replicated.

- Information about good design for housing for the person living with dementia is available, but not sufficiently accessible for the general population.

Chapter 5

Home Adaptations, Technology and Support

Chapter 5
Home Adaptations, Technology and Support

5.1 Adaptations and support

It is widely recognised by policy makers, practitioners and providers, as demonstrated in this report, that there is a need for appropriate new build housing solutions to meet the needs of older people and those with dementia. However, a major policy focus is through adapting their current living environment to create a safe and enabling home. In Homes Fit for the 21C, (2011c) Scottish Government indicates that adaptations are expected to rise from 66,300 (2008) to 88,000 by 2023 and 106,000 by 2033. However, the Scottish House Condition Survey 2011-13 indicates that this number may be higher, stating that 21% of all households in Scotland have in place adaptations for disabled occupants. This chapter will examine the needs of people with dementia in their own homes and the options available to them for adapting their homes to create an enabling and supportive environment.

5.2 Dementia friendly design

Dementia Friendly Design guidelines are widely available (Dementia Services Development Centre, 2013, King's Fund, 2015) which outline how to design living spaces to maintain the independence of people with dementia. The purpose of this report is not to detail the specific guidelines for creating dementia friendly environments; instead it will highlight the importance of considering dementia friendly design in all adaptations made to housing for people with dementia. Underpinning most dementia friendly guidelines is understanding how the consequences of dementia could create disability in some environments. Promoting using design approaches may compensate to some degree for these disabilities (Lawton, 1982). Examples of dementia friendly design include non-glare surfaces and having good colour contrast, which compensate for visuo-spatial difficulties as well as problems associated with the ageing eye.

5.3 Assessment

The authors consulted with professionals working in health, social care and housing in preparation for this report, and in particular, contacted Occupational Therapy leads for each area. From the responses it appears that the standard practice for adapting a home for a person with dementia is based on need. Individuals with dementia are referred to occupational therapist for an assessment when they are experiencing a specific problem in their home environment. Many of the people we spoke to discussed their concern over this. For example, they felt that local authority procurement processes might limit the type of equipment or adaptation

DESIGN FOR DEMENTIA: EXAMPLES OF EVIDENCE INFORMED GUIDANCE

Dementia Services Development Centre (DSDC), Joint Improvement Team (JIT), Chartered Institute for Housing (CIH) and University of Stirling (2013) Improving the design of housing to assist people with dementia
http://www.jitscotland.org.uk/resource/improving-housing-design-assist-dementia/

The Thomas Pocklington Trust (2014) Design Of Homes And Living Spaces For People With Dementia And Sight Loss: A Guide.
http://www.pocklington-trust.org.uk/project/design-of-homes-and-living-spaces/

Halsall Lloyd Partnership (2015) Design for Dementia Guide. This provides a illustrated guide for interior and exterior housing needs.
http://www.hlpdesign.com/images/case_studies/Vol1.pdf

that may be available to an historic list. This list of adaptations in terms of the definition of minor and major adaptations may be somewhat outdated and there is a revised, more flexible definition of adaptations in the Public Bodies Act guidance for Housing (Scottish Government, 2015e).

Further there was concern over the timing of the adaptations; overwhelmingly professionals working with people with dementia highlighted

Chapter 5
Home Adaptations, Technology and Support

the need for early intervention, to ensure the individual has the capability to adapt to changes. This is expected to diminish as the disease progresses. It is important housing policy recognise the needs and capabilities of people with dementia, timing of interventions in relation to the progression of dementia and especially in conjunction with post diagnostic support.

The Guidance on the Provision of Equipment and Adaptations (Scottish Government, 2009) is the principal national policy guidance on equipment and adaptations for Health, Housing and Social Care functions of public service. There are five main aims noted in the guidance with two specifically relating to joint working. These are as follows:

- Promote a consistent approach to the assessment for, and provision of, equipment and adaptations

- Promote good practice and partnership working in relation to equipment and adaptation provision

Significant levels of co-operation are required to ensure integrated working from care needs assessments to the co-ordination and carrying out of adaptation work. This requires a collaborative environment between a range of public services including housing, health and social care.

When my mum was getting less mobile, we were offered hoists and aids to help the carers get her up. We had real problems as they didn't go through the doorway from the bedroom. Without the hoist, the carers couldn't help her up. We ended up caring without help.

Mary, family carer.

In addition to formal assessment, it is important that people with dementia and their families are included in decisions about equipment and adaptations. Well planned home adaptations can increase feelings of security, safety and comfort by supporting personal routines within the home.

We just asked for the assessment and I made it clear that I wanted the bathroom to look as nice as it did now. We had to pay a bit extra but that was fine. I wouldn't accept just anything in my house.

Sandra, family carer

However, poorly planned adaptations can have negative impacts on individuals' wellbeing and independence.

It is important to ensure the design of home adaptations are person centred and as much as possible planned in conjunction with the home dweller and family member to ensure they are as successful as possible.

Bathing mum was a major problem. She preferred a bath to a shower. She had Alzheimer's and water hitting her skin caused her pain. She had become very sensitive to any kind of touch. When outside, she could not tolerate wind or rain. For that reason, showering was not possible and a walk-in shower room, as was the norm for elderly people with a disability, was not a good solution for her. Mum always loved a bath, she found it really relaxing. In addition, dad was her carer and he preferred a bath to a shower. However, it became increasingly difficult to get mum in and out of the bath. We were supplied with a very heavy electric bath seat which went up and down. She had to sit sideways on to the seat when it was raised and with help swing her legs round into the bath before being lowered. She found this procedure terrifying.

It is hard for families to know what is available and what would be helpful. It was only once mum was in care that I was aware of other aids which might have made life a bit easier at home.

  Jean, family Carer

5.4 Funding for home adaptations

For all adaptation requirements, the responsibility for assessment has been located with the Integrated Joint Boards. However, the process continues to be referral to Occupational Therapy services either via Social Work or Health services or through Health and Social Care partnership arrangements. Thereafter, adaptations such as stair lift, walk-in shower room or home extensions would have to be assessed as necessary and in the case of owner occupiers financially assessed. Some items of assistive equipment can be supplied free of charge if considered necessary. These include: specialist equipment such as bath hoists; shower seats; hand rails and other minor items which do not necessarily require an assessment, dependent on cost, as many are available through self referral from local Health and Social Care Boards. It is likely the picture is mixed as integration becomes embedded.

Chapter 5
Home Adaptations, Technology and Support

Advice from the Scottish Government in the Adaptations, Aids and Equipment (2014) delegates housing adaptations to Integration Authorities in accordance with the Public Bodies (Joint Working) (Scotland) Act (2014). The Integration Authority will be responsible for assessing care related needs and in most cases this will be carried out by an occupational therapist from local social work departments. The funding for these resources for adaptations will be assumed by the Integration Authority, who will have associated budgets, provide grants and advice and assistance where the person with care needs is not eligible for financial support (Scottish Government, 2014). However, funding for adaptations within the Housing Association sector is not included within the Integration Authorities.

While it is expected that national policy guidance be adhered to at a local level, it is a matter for local authorities to determine how such guidance is implemented and what priorities should occur. Having differing local authority policies and priorities for delivering adaptations within their Scheme of Assistance has led to some concerns about what might be funded by one Council might not be funded in another Council area (SPICe Briefing Housing Major Adaptations, Scottish Parliament, 2016b). Since April 2016, the responsibility for housing adaptations now lies with the Integration Authorities with duties previously established in the

Housing (Scotland) 2006 Act / Housing (Scotland) Act 2006 (Scheme of Assistance) Regulations 2008 and those located in Section 2 b of The Chronically Sick and Disabled Persons Act (Scottish Government, 1970).

Any adaptation is complicated on a practical level, by the provision of different adaptations that could impact on future occupiers of a property and the limitations of equipment that may need upkeep or replacement.

The key point to consider here is that adaptations must be assessed as necessary by an occupational therapist in order to access funding from the local authority across tenures (Scottish Government, 2009). These adaptations include "any alteration or addition to the structure, access, layout or fixtures of accommodation and any equipment or fittings installed or provided for use in accommodation, for the purpose of allowing a person to occupy or to continue to occupy, the accommodation as their sole or main residence" (The Scottish Government, 2014b).

This means that adaptations are only implemented after a problem has been identified. For individuals living in private rented or social housing, there is little scope for proactively adapting their home to ensure that it will meet their needs as they age. The available literature relating to creating dementia friendly environments, including the use of assistive technology and adaptations advocate the importance

CASE STUDY – 415 HUB INNOVATION PROJECT
SUPPORTING PEOPLE OVER 65 TO STAY IN THEIR OWN HOME FOR LONGER (LORETTO CARE, GLASGOW HOUSING ASSOCIATION, GLASGOW CITY COUNCIL)

415 Nitsdale Road is a project which was established in 2013 with the aim of supporting older people to stay in their homes for longer by informing them how to make adaptations to their homes to ensure they meet the future needs of the occupier. They identified a tower block of flats in Glasgow which had an ageing population and supported them to think about how to adapt their homes. Within the block, a demonstrator flat was developed to showcase adaptations for older people, with a range of health and physical needs, including dementia. This has been used to train health professionals, tenants and housing staff on how best to plan adaptations in advance.

Chapter 5
Home Adaptations, Technology and Support

of early intervention for individuals with dementia to ensure the success of the intervention (Alzheimer's Society, 2011). The current system of assessment and funding is based on priorities which may not align with these principles of early intervention, which is crucial across all health and social care needs and service user groups. Currently, referrals made for this early intervention approach are unlikely to be met within current pressures of demand for services and priority systems.

However, there are a number of financial schemes and initiatives which are designed to support owner occupiers to make adaptations to their homes, to allow them to live independently as long as possible. The Scottish Government initiative Help to Adapt is one such. Essentially, Help to Adapt is similar to Private Investment Equity Release Financial Products where a private investor takes a share of the equity of a person's dwelling. However, this scheme is funded by a Scottish Government loan, which is charged against the property and re-paid on sale of the property based on the loan to those people over 60 years old who are owner occupiers to consider making alterations to their property so that the dwelling can meet the occupier's future needs. This pilot scheme has now ended and it is important that lessons are learned from the experience of those people involved.

5.5 Care and Repair in Scotland

Care and Repair services operate in 31 of the 32 Local Authority areas in Scotland. Care and Repair aims to provide independent advice and support to people over the age of 65 and/or people with a disability or long term health condition to make changes and adaptations to their homes to enable them to live comfortably and safely.

In preparing this report, a scoping survey of Care and Repair Services in Scotland was carried out. This involved telephoning services in each Local Authority Area and completing a pro-forma with questions about the service. Responses were obtained from 15 of the 31 areas. The delivery of the services varied greatly across areas. Some Care and Repair Services were contained within larger Housing Associations or Local Authority Services, while others were stand-alone charity funded organisations. All of the Care and Repair Services we spoke to reported that they did provide support to people with dementia; however this support was not greatly different from the support provided to other people who used the service. Referrals to Care and Repair mostly come from occupational therapists; however some services accept direct contact for minor repairs from home owners.

Five of the care and repair services we spoke to indicated that some or all of

their staff had received basic dementia awareness training and that this was useful for supporting clients with dementia. These referred to making dementia specific adaptations to people's homes, for example thinking about colour contrast when fitting handrails or grab rails, and being aware of glare on materials. Additionally, care and repair managers said that dementia awareness training had helped the service in how they interact with their clients. For example, one service noted the importance of building up a relationship with the client, organising an initial meeting with the individual and their family. Two of the services spoke of the role their staff have recognising changing or developing housing related needs and informing health and social care staff.

While, there was some consideration of the needs of people with dementia, six of the Care and Repair services stated that the referral system they had in place meant that they would not necessarily know that the individual had dementia. Additionally, although many had an awareness of dementia friendly design guidelines and the importance of a well designed home for a person with dementia, all the services reported that the majority of the adaptations they made were for accessibility or physical need, for example grab rails and wet floor shower rooms. Only one service reported that they had had an occupational therapy referral, which specifically identified the need for coloured hand rails and non-glare flooring.

Overall, the Care and Repair services in Scotland have pockets of good practice, which demonstrates good knowledge and services for people affected by dementia, however there is great variation in services across Scotland. The view of many of the Care and Repair managers was that dementia has only relatively recently been recognised as something which needs to be considered in housing and so services were only just beginning to respond. It is clear that although work is underway to improve this, much still has to be done to ensure that people affected with dementia are receiving the appropriate support to making adaptations to their homes. Care and repair services have considerable potential in their reach and experience to play a key role in this process.

The Life Changes Trust have provided funding for three years to support an innovative approach in the "Care and Repair Dementia Enablement Pilot Project". This project resulted from raised awareness from Care and Repair Services highlighting the need for independent direct support for people living with dementia to remain at home. Over 200 people received supported in the first year. Currently they report that 70% of referrals for people living with dementia are from owner occupiers. Within the Angus area 50% of referrals (96 people) have come from the Dementia Post Diagnostic team, providing a good practice point in involving people with adaptations at an early stage. This co produced, positive

Chapter 5
Home Adaptations, Technology and Support

approach (see below) could inform
current approaches and be a model for
future practice within service provision.

POSITIVE APPROACH

CARE AND REPAIR DEMENTIA ENABLEMENT PILOT PROJECT

There is currently a three year pilot service being carried out in Aberdeen, Angus and Lochaber, Lochalsh and Skye to assist people living with dementia to remain independent.
The work is supported by the Life Changes Trust (a charity set up with a National Lottery annuity to assist people living with dementia and their unpaid carers and young people with experience of being in care). The dementia trained officer takes time to get to know the person and carries out a home assessment to see if there are any safety issues or particular difficulties being experienced and works with the person to resolve them. There are also pack items such as daylight bulbs, coloured grab rails, weekly wipe clean planner, digital calendar clock, thumb turn and privacy locks which can be fitted free of charge if they are felt to be needed.
The service is open to people in these areas living with dementia, going through diagnosis or presenting with signs of dementia. There is no minimum age. This is so that people are encouraged to get help in the early stages which they will more likely adapt to rather than waiting until significant work is required or relocation.

5.6 Assistive technology

There are many types of assistive technology available which could be beneficial for people affected with dementia. This includes mainstream technology such as smart phones and tablets, and more specialised technology such as adapted telephones and medication reminders and smart homes. In addition, the use of assistive technology is integral to telecare and telehealth services, which remotely support people affected by dementia to live independently in their own homes.

Alzheimer Scotland and the Alzheimer's Society both highlight the important role that assistive technology can play in supporting a person with dementia, however they also acknowledge that the appropriate support, training and assessment is required. This means that early intervention is important, as well as acknowledging that low tech solutions may be as successful in different circumstances as high tech ones (Alzheimer's Society, 2011, 2014b; Alzheimer Scotland, 2015).

The Technology Charter for People with Dementia in Scotland (Alzheimer Scotland, 2015) advocates the use of technology to support people with dementia in order for them to stay in their own homes for longer. Appreciating that society is becoming more reliant on technology the Charter aims to raise awareness of how technology can enhance the lives of people with dementia and their support networks. The key values which underpin the Charter is that the service is collaborative, rights based and personalised. Technological approaches are considered to augment and not replace human care and support.

Similarly, the Alzheimer's Society published a position paper in 2011 on the use of assistive technology for people with dementia (Alzheimer's Society, 2011). While it advocates the potential benefits of technology to the lives of people affected by dementia, it also highlights the need for an early intervention if the technology is to prove effective. This allows the person with dementia to have a choice in the type of technology they need and would like to use in order to provide better forward planning of care and support needs in the future. The paper highlights the existing problem is that people are often put off implementing assistive technology solutions until there is a significant problem, which because of the nature of dementia, is often too late for the person to adapt to the intervention, this can mean that it is often not an effective solution.

It is therefore important that technological interventions are considered at an early stage to maximise the impact in the individuals' life. However it is also important to consider that technological interventions may not be the solution for every person.

Chapter 5
Home Adaptations, Technology and Support

It should not replace human support and a person-centred assessment is required to ensure the intervention fits with the support needs and existing support plan of the individual.

5.7 Telecare and telehealth

Home automotive systems and assistive technologies can also be of great benefit and can provide healthcare and wellbeing benefits. Assisted Living Technology, for example the use of fall alarms, sensors for gas and water leaks and movement sensors can support independent living in the community. These 'telecare' measures can prevent or reduce admission to hospitals and care homes and can be personalised as required (Garrett et al., 2016).

For a person with dementia, telecare services can be used both to assist and monitor a person with dementia. Telecare measures may be simple such as accommodation that contains an alarm that is linked to a central point where a response is provided. However, telecare services can be personalised to meet the needs of an individual, which may provide more specific care and support. The case study above outlines how telecare services can be developed to support a person with dementia to allow them to live independently at home. The use of telecare in this situation allowed the lady with dementia to be monitored

in her own home without being restricted in her movements whilst giving their family reassurance that the person was safe living alone.

It is important to ensure that technology, telecare and telehealth are used appropriately for people living with dementia. Additionally, research has found that telecare and assistive technology may be limited if the wider model of support is not in place for example, telecare has been shown to be successful in areas where the underlying model of care is to promote and foster independence, however may not be as successful in an area with a more risk averse system. It is recommended that telecare provision be considered as part of the wider societal and political context (Bowes & McColgan, 2013).

There are issues around privacy, obtrusiveness and increasing isolation when using technology as an intervention for people with dementia (Chung, Demeris and Thompson, 2016; Sorell & Draper, 2012; Huang and Goldhaber, 2012). In particular, it is important to ensure that technology is not used as a substitute for human contact, which may further socially isolate and individual. Additionally, it is important to ensure people using the technology understand the purpose and the reporting of the data collected as well as being comfortable using it (Doughty & Williams, 2016). The final point to consider is that low tech interventions may be more useful to some individuals than high tech. This is described in the box below.

CASE STUDY

DEVELOPING PERSON CENTRED TELECARE SERVICES FOR A PERSON WITH DEMENTIA LIVING ALONE.

Mary, 83 was hospitalised after a fall in her own home, she lives alone but with family close by and they were keen that she was supported to live at home for as long as possible. Telecare services were introduced as part of her discharge package from hospital, including bed sensors and door sensors. However, as Mary's dementia progressed she began to get up more during the night, setting her bed sensor off and resulting in her family being called out numerous times throughout the night. The Telecare team were called in to reassess this and developed a person centred solution to allow Mary to safely move around the house during the night, while avoiding calling out her family but also monitoring her fall risk. Movement sensors were installed in all of her living areas which were connected up to the bed sensor. A 15 minute absence sensor was set on her bed sensor and when movement was detected in the living areas this reset the bed sensor allowing Mary to leave her bed and move around her home without alerting her family. To ensure she was still monitored for falls throughout the night, a PET filter was fitted on the PIR which only measured movement above a set level in the room. If Mary were to fall in any area of her home during the night, her family would be alerted that she needed assistance within 15 minutes. This problem orientated, person centred solution is supporting Mary to continue living in her own home independently.

Chapter 5
Home Adaptations, Technology and Support

5.8 Making use of 'everyday' technology

In the previous decade, advances in technology have seen devices being marketed which allow monitoring and controlling of many different aspects of daily living. Examples are wearable devices to monitor activity and sleep patterns, apps which allow you to control heating systems remotely and GPS technology, which allows location monitoring. Most of these solutions are controlled using a smart phone or tablet computer. Additionally, these technologies may prove useful to people living with dementia and/or their family carers.

As smart phones and tablet computers become more popular in day to day life,

CASE STUDY

LOW TECH SOLUTIONS

Jean, 80, lives alone. She was becoming very anxious when she saw her bathroom door closed over, thinking there was someone else in her home. A referral from the occupational therapist asked for a telecare solution to help support Jean. However, on assessment by the telecare specialist it was realised that a high tech adaptation was not required in this case. As Jean lived alone, there was no issue with the bathroom door not being shut as her front door was always locked. Instead, the local handyman service installed a door stop in the bathroom doorway meaning the door could not completely close. This low cost solution stopped Jean's anxiety about the closed door with little disruption to Jean's life or cost for the intervention.

people with dementia will increasingly use this type of technology. Recent statistics from Ofcom reveal that 71% of adults in the UK own a smart phone in 2016 (https://www.ofcom.org. uk/about-ofcom/latest/media/facts).

Looking to the future, it is important to consider that as people age, the use of smart technology will be an integral part of society. Therefore users may become adept in designing their own technological solutions using technology

CASE STUDY – EASYVIDEO

USING QR CODES TO SUPPORT INDIVIDUALS LIVING WITH DEMENTIA WITH EVERYDAY ACTIVITIES.

EasyVideo is a system where QR codes are fixed on or near household appliances which the user can scan with their smartphone or tablet computer and plays a video of how to use it. For example; scanning the kettle with an iPad and it plays a video of how to make a cup of coffee. These codes can be developed and person centred depending on the person's needs. The quote below is from a user of EasyVideo.

"I think EasyVideo is brilliant, I was really encouraged and thrilled to see such things existed because I am very computer literate myself… as I progress, not deteriorate, they will be very valuable and important to me to help remind me how to do things because we forget simple things"

DR BUTE, DIAGNOSED WITH DEMENTIA
http://www.inclusivemediasolutions.co.uk/testimonials/

Chapter 5
Home Adaptations, Technology and Support

generally available, without the need for formal assessment. Already there are a variety of smart phone apps, which have been designed to support people with dementia. Mindmate (http://www.mindmate-app.com/our-platform.html) is an app which is based on research evidence and developed at the University of Glasgow specifically to support people affected by dementia. There are clear benefits to the use of technology like this, although smart phone and tablet computers can be expensive, many apps are free or available for a minimal cost. In addition, as seen below, the use of QR codes to provide instructions on a smart phone on how to do everyday tasks in the home is becoming more popular as a way to support people with dementia in their own homes.

It is clear that as the population ages; the use of everyday technology will increase. Therefore policy, strategy and practice will need to adapt to ensure that people with dementia and their families are well supported in their technology choices and solutions to meet their care and support needs.

5.9 Use of assistive technology in Scotland

The Scottish Government has committed to improving and increasing the uptake of telecare services in Scotland by funding a number of projects through the Scottish Centre for Telecare and Telehealth. The Technology Enabled Care Programme has the most relevance to supporting people with dementia living in the community. The aims of this programme from 2014-2017 are to:

Extend the use of home health monitoring;

• Expand the use of video conferencing across all health and social care sectors, as well as growing its use for clinical/practitioner consultations;

• Build on the emerging national digital platforms to enable direct access to advice and assistance;

• Expand the take up of telecare with focus on prevention, points of transitions in care and dementia;

• Explore the scope and benefits of switching from analogue to digital telecare services.

This programme has provided funding to develop the Dementia Technology Charter in collaboration with Alzheimer Scotland, which is discussed above. It is clear that the view of the Scottish Government is that technology has

an important role to play in supporting people with dementia. However, it is important that we fully understand the potential benefits and uses of telecare and telehealth services for people living with dementia in Scotland.

An evaluation of the use of telecare for people with dementia in Renfrewshire, Scotland was carried out in 2013 (York Health Economics Consortium, 2013). The findings showed there were clear economic and social benefits of using telecare services to support people with dementia in their own homes. This included reducing unplanned hospital admissions, reducing delayed discharge from hospital, and an overall saving of £1.65 million over the 5 year evaluation period. However, there were drawbacks to the system such as the cost (£3.25 per week) putting people off using it, and for many people the introduction of the telecare system came too late to be of real benefit. This highlights the need for early intervention. Finally, there were accessibility problems for those who lived in social housing as many housing associations provided their own alarm and response system. Overall though, the evaluation of the service was positive in demonstrating the benefits of using telecare systems to support people with dementia living at home both for the individuals and the healthcare provider.

Recent work has investigated the feasibility of moving telecare services in Scotland from analogue to digital technology, with a heavier reliance on broadband and Internet services (Farrpoint Ltd, 2016). The findings from this work have indicated that upgrading to digital based services will:

- Improve the reliability and quality of Telecare services.

- Improve the efficiency of Telecare.

- Provide potential benefits by using digital technology to deliver new Telecare functionality and services.

- Provide potential benefits by using digital Telecare technology to support the delivery of Telehealth services.

Current statistics from the Scottish Government (2015a) estimate that around 80% of households have Internet access in Scotland, however those in social housing were less likely to have Internet access than in other tenures, with only 62% of social housing tenures having home Internet access. Additionally, internet usage is reported to reduce as people age, with 69% of 60-74 year olds using the internet, compared to only 30% of those aged 75 and over. If there is a move to digital telecare services, this should be considered as it may introduce inequities in service provision. Additionally, the proliferation of providers and the move to seeking the best options, suggests that that telecare technology needs the flexibility to move interchangeably between these.

Chapter 5
Home Adaptations, Technology and Support

This chapter has discussed some of the adaptation and support options available to people with dementia living in their own homes. There is limited research evidence on the efficacy of physical adaptations to the home. A general review by Heywood and Turner (2000) of health and social care clearly identify the challenges of measuring effectiveness with such a range of needs but did not specifically identify the person affected with dementia. It should be recommended that any physical adaptations should take account of Dementia Friendly Design guidelines. Additionally, there is a range of technological solutions, which may help to support a person with dementia living at home. These include telecare services, specific assistive technologies and perhaps becoming more relevant, everyday technologies.

Key findings:

- Given the current lack of suitable housing supply, it is important to consider how to adapt existing housing stock to meet the needs of people with dementia, across all tenures.

- All home adaptations should be considered as early as possible, to ensure the needs of people with dementia are person centred, well planned and can promote living well at home for as long as possible.

- Home adaptations should address the cognitive and psychological needs of people living with dementia as well as physical support.

- The role of technology to support people with dementia at home is important. However technology is advancing rapidly and people with dementia need to be supported to adapt and use mainstream technology.

Chapter 6

Conclusion

Chapter 6
Conclusion

The aim of this project was to develop a comprehensive overview of the current housing situation for people affected by dementia including the existing full range of housing options, solutions, services and supports. This required a review of current policies, scoping of current practice and services and engagement with people with dementia, family, other carers and professionals from dementia health, social and integrated care, housing and spatial planning as well as design.

There is a paucity of robust evidence and research related to dementia housing and design and it has been necessary to draw upon data and policy in relation to housing and planning for older age and the needs of older people. There is such limited specialist provision for people with dementia that evidence for this specific group of people is missing. The key findings reflect this and recognise that although dementia is often thought to be a condition related to old age, young onset dementia is also on the increase and people with Down's Syndrome are prone to developing dementia at a relatively young age. These groups may need focussed research on their specific circumstances.

The majority of specialised housing is in the social housing sector with less than 10% of such housing been in the private sector. 23% of older people in Scotland live in Social Housing, compared to 73% own their own homes and 4% live in private rented accommodation. Data on housing occupation, types and tenures of those with dementia does not exist and there is a need for research and evidence in this area, as only between a fifth and a quarter of older people, and it follows older people with dementia, currently live in social housing.

Housing is considered to be important by people, both young and older, living with dementia, family and health and social care practitioners. Housing as an aspect of living well with dementia is underdeveloped within the current integration agenda of health and social care. There is a need to develop outcomes and evidence about adaptations in the home, including technological innovations. Clear information and timely intervention related to housing needs and adaptations can be difficult to source. Additionally, while most strategies and policies about dementia refer to housing and many of those about housing refer to dementia, this connection needs to be more integral and explicit. Explicit policy and strategies about housing and dementia are required, clearly identifying the interrelation impacting on living well in the community.

The community empowerment agenda brings a greater push for more 'bottom up' approaches for communities to shape their own place including the opportunity to participate in the provision of good quality housing for older people and those with dementia. The community and voluntary sector specialising in older

people's housing and dementia need to participate in the preparation of local development plans to ensure needs and demands of older people and those with dementia are reflected in future plan policy. Housing development does not focus sufficiently on older people's housing. Greater opportunity for private housing supply that could support the person living with dementia should be explored and developed. A key tool to shape the supply of private housing for older people and those with dementia is through planning policy. If specific requirements for such housing was accommodated within planning policy documentation then this would oblige private developers to provide an element of housing for such purposes. Such policies should be included in both National policy documents such as SPP and the National Planning Framework (NPF) as well as forming part of local development plans.

The person with dementia, their family and supporters need appropriate housing and support to live well. This is influenced by a wide range of stakeholders from policy makers to front line workers in housing, health, social care and the third sector. However, specific housing and dementia policy is not aligned or integrated. The developing opportunities for leadership around housing from health and social care partnerships should be supported and strengthened.

Housing policy and planning should support an increase in the range of housing options, both public and private, to meet the needs of the person with dementia and their family. Within public and private housing there should be increased choice, not only to support people who wish to move to appropriate accommodation, but also to provide early interventions to adapt the person's current home.

Provision of information and advice is crucial to positive decision-making. This requires development to find ways to make information about housing design, adaptation, technology and support available to the person with dementia, their family and supporters. The provision of an online resource is suggested as one way of widening access for all.

Staff within a range of housing related organisations are very well placed and should be appropriately trained to support the person with dementia. Recognising the complexity and diversity of the needs of people affected by dementia, housing should be part of an integrated service playing its role to the full.

This report has sought evidence from a wide range of stakeholders and highlights a lack of research evidence about the needs and preferences of people with dementia, the efficacy of adaptations and support at home and the impact of change and choice of tenure. In order to meet the recommendations suggested within this report, further research is urgently required to fully understand the housing needs and experiences of people living with dementia in Scotland.

References

References

Alzheimer Scotland (2015) Technology Charter for People Living with Dementia. [Online] Available http://www.alzscot.org/assets/0002/0289/Technology_Charter_for_People_with_Dementia_in_Scotland.pdf [Accessed 8th August, 2016].

Alzheimer Scotland (2017) Statistics [Online] Available http://www.alzscot.org/campaigning/statistics [Accessed 16th August, 2016].

Alzheimer's Society (2011) Assistive Technology [Online] Available https://www.alzheimers.org.uk/download/downloads/id/1098/alzheimers_society_position_paper_on_assistive_technology.pdf [Accessed 6th August, 2016].

Alzheimer's Society (2012) Home truths: Housing services and support for people with dementia [Online]. Available https://www.alzheimers.org.uk/site/scripts/download_info.php?fileID=1452 [Accessed 16th August 2016].

Alzheimer's Society (2013) Low expectations: Attitudes on choice, care and community for people with dementia in care homes. [Online] Available https://www.alzheimers.org.uk/site/scripts/download_info.php?downloadID=1024 [Accessed 14th September 2016].

Alzheimer's Society (2014a) YouGov poll [Online]. Available: https://www.alzheimers.org.uk/site/scripts/news_article.php?newsID=2065 [Accessed 5th December 2016].

Alzheimer's Society (2014b), Dementia UK: update, London. [Online] Available https://www.alzheimers.org.uk/dementiauk [Accessed 16th August, 2016].

Alzheimer's Disease International (2014) World Alzheimer Report 2014. [Online] London Alzheimer's Disease International https://www.alz.co.uk/research/WorldAlzheimerReport2014.pdf [Accessed 18th August 2016].

Architecture and Design Scotland, NHS Health Scotland and Scottish Government (2016) Place Standard [Online] Available https://placestandard.scot [Accessed 6th November 2016].

Barret, J (2012) Housing and Dementia Research Consortium Report: Provision for people with dementia within Housing with Care [Online] Available: https://housingdementiaresearch.files.wordpress.com/2012/07/report-on-provision-for-people-with-dementia_v1-6_jun2012.pdf [Accessed 12th may 2016].

Benner, M., Steiner, V. and Pierce, L.L. (2016) Family caregivers' reports of hospitalizations and emergency department visits in community-dwelling individuals with dementia. Dementia, p.1471301216653537.

Black, B.S., Johnston, D., Rabins, P.V., Morrison, A., Lyketsos, C. and Samus, Q.M. (2013). Unmet Needs of Community – Residing Persons with Dementia and Their Informal Caregivers: Findings from the Maximizing Independence at Home Study. Journal of the American Geriatrics Society, Vol. 61(12), pp.2087-2095.

Bookman, A. (2008) Innovative models of aging in place: Transforming our communities for an aging population. Community, Work & Family, Vol. 11(4), pp.419-438.

Bowes, A. and McColgan, G. (2013) Telecare for Older People: Promoting Independence, Participation, and Identity. Research on Aging. Vol.35(1), pp.32-49.

Chartered Institute of Housing (2016) Dementia Pathways. Housing's Role: Key Research Findings. [Online] Available http://www.cih.org/resources/PDF/Scotland%20Policy%20Pdfs/Dementia/Dementia%20Research%20Findings%20Complete%20FINAL.pdf [Accessed 10th March 2017].

Chippendale, T. L. and Bear-Lehman, J. (2010) Enabling 'Ageing in Place' for urban dwelling seniors: An Adaptive or remedial approach? Physical & Occupational Therapy in Geriatrics. Vol. 28 (1), pp.57–62.

References

Chung, J., Demiris, G., and Thompson, H. J. (2016) Ethical Considerations Regarding the Use of Smart Home Technologies for Older Adults: An Integrative Review. Annual Review of Nursing Research. Vol.34 pp.155-181.

COSLA and The Scottish Government (2010) Wider planning for an ageing population - housing and communities. Consultation on the workstream report and its suggested actions. Edinburgh, Crown Copyright.

Dawson, A., Bowes, A., Kelly, F., Velzke, K. and Ward, R., 2015. Evidence of what works to support and sustain care at home for people with dementia: a literature review with a systematic approach. BMC geriatrics, Vol.15(1), p.1.

Dementia Care (2015) Housing Options for People with Dementia Report, Newcastle on Tyne: Dementia Care.

Dementia Services Development Centre (2013) Improving the design of housing to assist people with dementia [Online]. DSDC, Stirling. Available: http://www.cih.org/resources/PDF/Scotland%20general/Improving%20the%20design%20of%20housing%20to%20assist%20people%20with%20dementia%20-%20FINAL.pdf [Accessed 16th September 2016].

Department of Health (2015) Prime Minister's challenge on dementia 2020 [Online]. Crown Copyright, London. Available: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/414344/pm-dementia2020.pdf. [Accessed 16th September 2016].

Doughty, K., and Williams, G. (2016) New models of assessment and prescription of smart assisted living technologies for personalised support of older and disabled people. Journal of Assistive Technologies. Vol.10(1), pp.39-50.

Duane, F., Brasher, K. and Koch, S (2013) Living alone with dementia. Dementia. Vol12(1), pp. 123-136.

Ewen, H. H., Hahn, S. J., Erikson, M. A. and Krout, J. A. (2014) Ageing in Place or Relocation? Plans of Community-Dwelling Older Adults. Journal of Housing for the Elderly. Vol.28, pp.288–309.

Farrpoint Ltd. (2016) Feasibility Study: Telecare in Scotland Analogue to Digital Transition. [Online] Available https://sctt.org.uk/wp-content/uploads/2016/09/Product-2-and-3-Final-Report-Issued.pdf [Accessed 12th November, 2016].

First stop Advice (2015) Facts and Figures [Online] Available http://www.firststopcareadvice.org.uk/facts-and-figures/ [Accessed 20th November, 2016].

Gabriel, M., Faulkner, D. and Stirling, C. (2015) Housing priorities of people with dementia: security, continuity and support. AHURI Final Report No. 242 [Online]. Victoria: Australian Housing and Urban Research Institute. Available: https://www.ahuri.edu.au/research/final-reports/242. [Accessed 29th September 2016]

Garrett, H., Roys, M., Burris, S. and Nicol, S. (2016) The cost-benefit to the NHS arising from preventative housing interventions. IHS, Herts.

Gibson, A.K., Anderson, K.A. and Acocks, S. (2014) Exploring the service and support needs of families with early-onset Alzheimer's disease. American Journal of Alzheimer's Disease & Other Dementias, Vol 29(7), pp.596-600.

Gibson, G., Newton, L., Pritchard, G., Finch, T., Brittain, K. and Robinson, L., (2016). The provision of assistive technology products and services for people with dementia in the United Kingdom [Online]. Dementia, Vol. 15 (4) pp 681–701.

Home2fit (ND) [Online] Available https://www.housingoptionsscotland.org.uk/2014/05/home2fit-scotlands-accessible-housing-register/ [Accessed 30th October 2016].

References

Heywood, F. and Turner, L. (2000) Better Outcomes: Lower Costs. Implications for health and social care budgets of investment in housing adaptations, improvements and equipment: a review of the evidence [Online] Available http://webarchive.nationalarchives.gov.uk/+/http:/www.officefordisability.gov.uk/docs/better_outcomes_summary.pdf [Accessed 13th May, 2017].

Huang, C. J., and Goldhaber, T. S. (2012) Malicious meddling or transparent tracking? Telecare as a logical extension of modern communications technology. The American Journal of Bioethics: AJOB. Vol.12(9), pp.45-47.

Information Services Division (ISD) (2014) Care Home Census 2014. [Online] Available https://www.isdscotland.org/Health-Topics/Health-and-Social-Community-Care/Publications/2014-10-28/2014-10-28-CHCensus-Report.pdf [Accessed May 2016].

Joint Improvement Team and the Chartered Institute for Housing (2013) Improving Housing and Housing Services for People with Dementia: Housing and Dementia Survey [Online] available at http://www.jitscotland.org.uk/wp-content/uploads/2014/10/Improving-Housing-and-Housing-Services-for-People-with-Dementia-Feedback-Survey.pdf [Accessed 29th September 2016]

Joint Improvement Team (2015) Action Area: Housing. [Online] Available: http://www.jitscotland.org.uk/action-area/housing/ [Accessed 3rd October, 2016].

Joint Improvement Team and NHS Scotland (2016) Anticipatory Care Booklet [Online] Available: http://www.jitscotland.org.uk/wp-content/uploads/2015/01/Final-A5-Anticipatory-Care-booklet-v6.pdf [Accessed 29th September 2016]

Lawton MP (1982). Competence, environmental press, and the adaptation of older people. In: Lawton MP, Windley PG, Byerts TO, (eds). Aging and the environment. New York: Springer p. 33-59.

Lithgow, S, Jackson, GA and Browne, D (2012). Estimating the prevalence of dementia: Cognitive screening in Glasgow nursing homes. Int J Geriatr Psychiatry Vol. 27(8), pp785–791.

Lowton, K., Laybourne, A. H., Whiting, D. G., and Martin, F. C. (2010) Can Fire and Rescue Services and the National Health Service work together to improve the safety and wellbeing of vulnerable older people? Design of a proof of concept study. BMC Health Services Research. Vol.10 pp.327-327.

McFadden, E. S. and Lucio, J. (2014) Aging in (Privatized) Places: Subsidized Housing Policy and Seniors. Journal of Housing for the Elderly. Vol.28, pp.268–287.

Milligan, C., Dowrick, C., Payne, S., Hanratty, B., Irwin, P., Neary, D. and Richardson, D. (2013). Men's Sheds and other gendered interventions for older men: improving health and wellbeing through social activity-a systematic review and scoping of the evidence base. Lancaster: Lancaster University Centre for Ageing Research.

Miranda-Castillo, C., Woods, B. and Orrell, M. (2010) People with dementia living alone: what are their needs and what kind of support are they receiving? International Psychogeriatrics. Vol.22(4), pp.607-617.

National Housing Federation (ND) Dementia: Finding housing solutions. [Online] Available: https://www.housinglin.org.uk/_assets/Resources/Housing/OtherOrganisation/Dementia_-_Finding_housing_solutions.pdf [Accessed 14th October, 2016].

National Records of Scotland (2014) Household Projections for Scotland, 2012-based [Online]. Available: http://www.nrscotland.gov.uk/files/statistics/household-projections/2012-based/html/household-projections-2012-results.html [Accessed 20th August, 2016].

Office for National Statistics (2011) 2011 Census [Online] Available https://www.ons.gov.uk/census/2011census [Accessed 8th September, 2016].

References

Royal Town Planning Institute (RTPI) (2017) Dementia and Town Planning. [Online] Available: http://rtpi.org.uk/knowledge/practice/dementia-and-town-planning/ (Accessed 30th January, 2017).

Scotland's Housing Network (2017) Adapting for Change Improvement Programme. [Online] available http://www.scotlandshousingnetwork.org/health-social-care/adapting-for-change/. [Accessed 12th May, 2017].

Scottish Government (1970) Chronically Sick and Disabled Persons Act. [Online] Available: http://www.legislation.gov.uk/ukpga/1970/44/contents [Accessed 12th May, 2017].

Scottish Government (2007) All Our Futures: planning for a Scotland with an ageing population [Online]. Available http://www.gov.scot/Publications/2007/03/08125028/0 [Accessed 12th October 2016].

Scottish Government (2009) Guidance on the Provision of Equipment and Adaptations. [Online] Available www.scotland.gov.uk/Topics/Health/care/EandA/EandAGuidance. [Accessed 8th September 2016].

Scottish Government (2010) Scotland's National Dementia Strategy 2013-2016 [Online]. Available http://www.gov.scot/Resource/Doc/324377/0104420.pdf [Accessed 25 Aug 2016].

Scottish Government (2011a) Standards of Care for Dementia in Scotland. [Online] Available http://www.gov.scot/Resource/Doc/350188/0117212.pdf [Accessed 20th August, 2017]

Scottish Government (2011b) Promoting Excellence: A framework for all health and social services staff working with people with dementia, their families and carers. [Online] Available http://www.gov.scot/resource/doc/350174/0117211.pdf [Accessed 17th August, 2016].

Scottish Government (2011c) Homes Fit for the 21st Century: The Scottish Government's Strategy and Action Plan for Housing in the Next Decade: 2011-2020. [Online] Available: http://www.gov.scot/Publications/2011/02/03132933/0 [Accessed 24th October, 2017].

Scottish Government (2011d) Age, home and community: A strategy for housing for Scotland's older people: 2012 – 2021 http://www.gov.scot/Resource/Doc/365373/0124256.pdf [Accessed 24th October, 2017].

Scottish Government (2013a) Scotland's Dementia Strategy [Online]. Available: http://www.gov.scot/Topics/Health/Services/Mental-Health/Dementia/DementiaStrategy1316. [Accessed 16th August 2016].

Scottish Government (2013b) Scotland's Sustainable Housing Strategy. [Online] Available: http://www.gov.scot/resource/0042/00425697.pdf [Accessed 24th October, 2016]

Scottish Government (2013c) Planning Series Circular 6/2013: Development Planning. [Online] Available http://www.gov.scot/Publications/2013/12/9924 [Accessed 9th September 2016].

Scottish Government (2014) Scottish House Condition Surveys 2012-2014. [Online] Available http://www.gov.scot/Publications/2015/12/8460 [Accessed 10th August, 2016].

Scottish Government (2014a) Scottish Planning Policy. [Online] Available http://www.gov.scot/Topics/Built-Environment/planning/Policy [Accessed 5th September, 2016].

Scottish Government (2014b) Adaptation, Aids and Equipment Advice Note. [Online] Available: http://www.gov.scot/Resource/0047/00476043.pdf [Accessed 12th April, 2017].

Scottish Government (2014c) Scottish Household Survey Annual Report. [Online] Available http://www.gov.scot/Publications/2014/08/7973 [Accessed 5th July, 2016].

Scottish Government (2014d) Public Bodies (Joint Working) (Scotland) Act 2014. [Online] Available http://www.legislation.gov.uk/asp/2014/9/pdfs/asp_20140009_en.pdf [Accessed 12th September, 2016].

References

Scottish Government (2015a) Review of the Scottish Planning System. [Online] Available http://www.gov.scot/Topics/Built-Environment/planning/Review-of-Planning [Accessed 9th November, 2016].

Scottish Government (2015b) National Health and Wellbeing Outcomes Framework. [Online] Available http://www.gov.scot/Publications/2015/02/9966/downloads [Accessed 8th November 2016].

Scottish Government (2015c) Review of the Scottish Planning System. [Online] Available http://www.gov.scot/Topics/Built-Environment/planning/Review-of-Planning [Accessed 9th November, 2016].

Scottish Government, (2015d) Joint Housing Delivery Plan for Scotland (JHDP) [Online] Available http://www.gov.scot/Publications/2015/05/3392 [Accessed 28th November, 2017].

Scottish Government (2015e) Community Empowerment (Scotland) Act. [Online] Available http://www.gov.scot/Topics/People/engage/CommEmpowerBill [Accessed 9th September, 2016].

Scottish Government (2015e) Adaptations, Aids and Equipment The Public Bodies (Joint Working) (Prescribed Local Authority Functions etc.) (Scotland) Regulations 2014 [Online] Available http://www.gov.scot/Publications/2015/04/9832/downloads [Accessed 12th May, 2017].

Scottish Government (2016a) Proposal for Scotland's National Dementia Strategy 2016-19. [Online]. Available http://www.gov.scot/Topics/Health/Services/Mental-Health/Dementia/March [Accessed 25th august, 2016].

Scottish Government (2016b) SPICe Briefing Housing Major Adaptations, Scottish Parliament [Online] Available http://www.parliament.scot/ResearchBriefingsAndFactsheets/S4/SB_16-27_Housing_Adaptations_Major.pdf [Accessed 10th May 2016].

Scottish Government (2016c) High Level Summary of Statistics Trend Tenure. [Online] Available http://www.gov.scot/Topics/Statistics/Browse/Housing-Regeneration/TrendTenure [Accessed 5th September 2016].

Scottish Government (2016d) Housing Statistics for Scotland. [Online] Available http://www.gov.scot/Topics/Statistics/Browse/Housing-Regeneration/HSfS [Accessed 12th January 2017].

Scottish Government (2016e) Scottish Household Survey Annual Report http://www.gov.scot/Topics/Statistics/16002/PublicationAnnual. [Accessed 12th January, 2017].

Scottish Government (ND) Housing Need and Demand Assessment Tool. [Online] Available http://www.gov.scot/Topics/Built-Environment/Housing/supply-demand/chma [Accessed 4th November 2016].

Scottish Government and COSLA (2010b) The Wider Planning for an Ageing Population report [Online] Available http://www.gov.scot/resource/doc/316308/0100676.pdf [Accessed 24th October, 2016].

Sharp, B. (2015) Stress as Experienced by People with Dementia: An Interpretative Phenomenological Analysis. Unpublished PhD Thesis, University of the West of Scotland.

Simmons, J and Atkins, S (2013) Aging in the community. Generations, Journal of the American Society on Aging. Winter Issue.

Sorell, T. and Draper, H., (2012) Telecare, surveillance, and the welfare state. The American Journal of Bioethics, Vol.12(9), pp.36-44.

Soto, M., Andrieu, S., Gares, V., Cesari, M., Gillette – Guyonnet, S., Cantet, C., Vellas, B. and Nourhashémi, F. (2015). Living alone with Alzheimer's disease and the risk of adverse outcomes: results from the plan de soin et d'aide dans la maladie d'Alzheimer study. Journal of the American Geriatrics Society, Vol. 63(4), pp.651-658.

Svanström, R., 2015. Fragmented Existence: Living Alone with Dementia. In Dick-Muehlke, C., Orleans, M. and Li, R. (eds) (2015) Psychosocial Studies of the Individual's Changing Perspectives in Alzheimer's Disease, p.302.

References

The King's Fund (2015) Environments of care for people with dementia [Online] Available https://www.kingsfund.org.uk/projects/enhancing-healing-environment/ehe-in-dementia-care [Accessed 16th October, 2016].

Tolson, D. Ritchie, L., Danson, M. and Banks, P. (2016). Dementia in the workplace: the potential for continued employment post diagnosis [Online]. Available https://www.researchgate.net/publication/303497370_Dementia_in_the_Workplace DOI:10.13140/RG.2.1.4131.1601 [Accessed 5th May, 2017].

UK Government (2010) Equality Act. [Online] Available http://www.legislation.gov.uk/ukpga/2010/15/contents [Accessed 4th July 2016].

United Nations (ND) Convention on the Rights of Persons with Disabilities. [Online] Available http://www.ohchr.org/EN/HRBodies/CRPD/Pages/ConventionRightsPersonsWithDisabilities.aspx [Accessed 8th September, 2016].

van Hoof, J., Kort, H.S., van Waarde, H. and Blom, M.M. (2010). Environmental interventions and the design of homes for older adults with dementia: an overview. American journal of Alzheimer's disease and other dementias, Vol. 25(3), pp.202-232.

Viewpoint (2016) Living Well with Dementia: Dementia Strategy 2016-2020. Edinburgh: Viewpoint.

Whelan, PJ et al (2013). Impact of the demand for 'proxy assent' on recruitment to a randomised controlled trial of vaccination testing in care homes. J Med Ethics Vol. 39(1), pp36–40.

Wood, C. (2013) Demos, The Top of the Ladder. [Online]. Available: https://www.demos.co.uk/files/TopoftheLadder-web.pdf?1378922386 [Accessed 15th October, 2016]

World Health Organization (2007) Global Age-Friendly Cities a Guide [Online]. Global age-friendly cities: A guide. Geneva: World Health Organization. Available http://www.who.int/ageing/publications/Global_age_friendly_cities_Guide_English.pdf [Accessed 23 Aug 2016].

World Health Organization (2016) Dementia [Online] http://www.who.int/mediacentre/factsheets/fs362/en/ [Accessed 14th August 2016]

York Health Economics Consortium (2013) Telecare for people with dementia: Evaluation of the Renfrewshire Project. [Online] Available http://www.scie-socialcareonline.org.uk/search?q=publisher_name%3A%22york+health+economics+consortium%22&f_author_editor_name_facet=YORK+HEALTH+ECONOMICS+CONSORTIUM&page=1 [Accessed 8th August 2016].

Appendix

Appendix

Housing and Dementia Prototype Online Resource

Following a review of the current housing situation for people with dementia in Scotland, a prototype online resource has been designed with the intention of showing an example of a 'One Stop Shop'. This would be envisaged as an information portal with provisions for a discussion forum to enhance opportunities for peer support. It could be helpful for people living with dementia, their carers, families, health professionals and housing professionals, where they can access a wide range of information that is currently only available piecemeal. A prototype online resource was created by BRE http://bregroup.com/dip/ together with a proposed website layout. This outlines the headings and content of each section of the website. It also demonstrates how the individual pages connect together.

What we did

Two focus groups were held at University of West of Scotland's Hamilton Campus, with a range of sector representatives including:

- local authority housing department staff

- local authority policy advisors

- carers

- day care staff

- advocacy teams

- community nurses

The project team also presented the website architecture and online prototype to a group of people living with dementia, family and carers at the Dementia Cafes in Lanarkshire. Most older people there felt that the portal was a great idea for others, but that they wouldn't use it personally as they do not use computers.

A group of members of the Scottish Dementia Working Group provided some commentary at a meeting with our Alzheimer Scotland team member.

The project team gave an overview of the project plans and outcomes to date. and presented the proposed website layout and the prototype for comment.

A number of questions were used to guide discussions, but generally the discussions followed the participants and focused on content and layout. The questions were in two parts, covering the site layout and the web design.

Feedback is integrated and reported here:

General feedback included a general response that the portal was likely to be useful and should be developed further. The resource should be called a **'One Stop Shop'** with clear links to other sources and websites for more detailed information.

People living with dementia suggested that using video and pictures and less clutter and text. The use of 'virtual tours' was advised. Terms should be clearly defined and language should be jargon free. The colour and text needs to be checked with a range of people to make sure the colour and design was accessible.

Content was examined in some detail by these groups and a range of suggestions made to add a range of headings under each topic. It is clear from the extensive list generated by all group and individual discussion that information is complex, wide ranging and indivualised.

A full list of the topics is available from the authors.

A range of additional information was suggested with new headings including:

Rights and Benefits based on a Charter of Rights for People with Dementia, council tax exemptions, financial entitlements, post-diagnosis right to support, links to Princess Royal Trust for Carers.

Assistive Technology with guides to potential suppliers of technology and products and legal issues related to technology.

People under 65 years living with dementia should be a particular section with information / support specific to this age group. This might include the right to continue to work, that life doesn't stop and about living well with dementia.

Emergency Contacts as a new heading could include Local Authority, fire service, police and Alzheimer Scotland.

Appendix

Engagement and feedback

A discussion forum was felt to be a very useful feature - almost everyone said they would use the discussion forum. This could be used to discuss concerns that are likely to crop up that would not be captured by a generic site. This included being able to ask questions and receive some response. This would require management of the site and would also ensure this was up to date and dynamic, including the use of a newsfeed feature.

It is clear from this consultation that most of those involved were enthusiastic about an online resource. Even if the person was unlikely to use this, they were able to identify the potential for others, such as family members and professionals to benefit from this integrated source of up to date information. Practitioners suggested that a resource such as this would be an aid to greater integration of current knowledge and a resource to offer people living with dementia, family members and supporters. This is particularly important for those people who are living in privately rented and owner occupier accommodation, where there can be less immediate support and information.