Research for Dementia and Home Design in Ireland looking at New Build and Retro-Fit Homes from a Universal Design Approach:

Key Findings and Recommendations Report 2015

Centre for Excellence in Universal Design

National Disability Authority
Údarás Náisiúnta Míchumais

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Key Findings and Recommendations Report 2015
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Centre for Excellence in Universal Design

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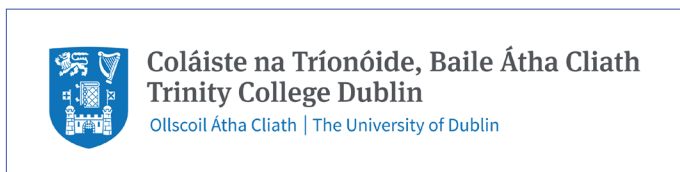
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- **education and professional development**

- **raising awareness of universal design**

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Minister's Foreword

It is important that people with dementia are facilitated to remain living at home and in their community independently and safely for as long as possible. The research commissioned by the National Disability Authority's Centre for Excellence in Universal Design and the related design guidance will be key to informing the design of dementia-friendly housing, using the Universal Design approach.

I believe that this research and associated design guidelines can inform national policy and can be used in practice by all stakeholders – those who commission, design, build, provide and occupy housing. Designing and building new homes or making alterations to existing homes that are in line with a Universal Design dementia-friendly approach will support the aim of the Irish National Dementia Strategy to facilitate people with dementia to live well for as long as possible. This approach will also support family members and carers to sustain the caring relationship, particularly if these carers are older people or they themselves have a disability. I would hope to see this information and guidance reach the widest possible audience, and that it is being acted on.

Ireland is unique in having a statutory Centre for Excellence in Universal Design, part of the National Disability Authority, which promotes the design of environments, products, services and technologies that take account of human difference, and can be used by anyone regardless of age, size, ability or disability. We all have a role to play in ensuring the universal design approach is adopted in practice, making our environment easy for all of us to use.

I would like to thank all the individuals and organisations who have engaged with this work and whose feedback has informed the outcome. I would like to also thank the authors from the Living with Dementia Programme at the Dementia Services Information and Development Centre St James Hospital, Dublin & School of Social Work and Social Policy, Trinity College Dublin and TrinityHaus, School of Engineering, Trinity College Dublin for their work on this report.

Kathleen Lynch, T.D.

Minister of State for Primary Care, Social Care and Mental Health

Chairperson's Foreword

There are about 48,000 people with dementia in Ireland. This number is expected to double by 2031. Although about two-thirds of people with dementia are living in their own homes, there has been an absence to date in Ireland and internationally of design guidance for domestic dwellings for people with dementia, their families and carers. Aware of this gap, the National Disability Authority Centre of Excellence in Universal Design commissioned this collaborative research project combining expertise in dementia and in architecture.

The research was carried out by Trinity College Dublin's Living with Dementia programme in the School of Social Work and Social Policy, and TrinityHaus in the School of Engineering. The purpose of this study was to inform the development of design guidelines, to guide built environment professionals such as architects, planners, landscape architects, quantity surveyors, engineers and builders, as well as health service professionals, on how to produce dementia-friendly new housing or to retro-fit people's existing homes, using a Universal Design approach. Universal Design means the design of an environment, product or service so that it can be accessed, used and understood to the greatest extent possible by everyone, regardless of age, size, ability or disability.

The research involved engagement with built environment professionals, health service professionals, people with dementia, their families and carers, as well as drawing on the body of literature in the field. This work shows that the built environment can be designed to help compensate for the memory, cognitive, sensory and other changes associated with dementia and to positively support people with dementia to remain in their own homes, enjoy a good quality of life and live as independently as possible. The report looked at design factors to serve the interlinked needs of people living with dementia, and their families and carers.

We hope that this Research and Recommendations report will be useful and will be read and used by all those directly affected by dementia and in particular by policy makers, planners, built environment professionals and the myriad of other allied health professionals and other service providers working in the field of dementia care in Ireland.

Helen Guinan

Chairperson
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Acknowledgements

Photographs:

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Tom Grey is a Research Fellow in TrinityHaus, School of Engineering, Trinity College, Dublin. His training as an architect and experience in architectural practice help to inform his research around Universal Design and the built environment.

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Executive Summary

Dementia is an umbrella term used to refer to a group of diseases that have broadly similar symptoms but different causes, including Alzheimer's disease and Vascular Dementia. While there is at present no cure for the diseases that cause dementia, there is much that can be done to maximise the quality of life for those living with dementia through appropriate activities and therapies. Good design of the homes where people with dementia and their families live can support people with dementia to continue to live independently and safely in their own homes and have a positive impact on their quality of life.

In Ireland about 30,000 people with dementia live at home in the community, and another circa 18,000 live in long-stay residential care. With population ageing, the number of people living at home in the community with dementia is expected to double to about 60,000 by 2031. It is therefore an important challenge to design today's and tomorrow's homes in a dementia-friendly way that promotes the wellbeing and independence of people with dementia, and takes account of the needs of their family and other carers. A Universal Design process that engages sensitively with individuals with dementia as well as their family and other carers is likely to produce more successful results.

This Research and Recommendations Report, commissioned by the Centre for Excellence in Universal Design at the National Disability Authority, builds on other key pieces of work the Centre has produced – Building for Everyone: A Universal Design Approach and Universal Design Guidelines for homes in Ireland. The research included a review of relevant national and international literature, in-depth interviews with key stakeholders including people with dementia and their family carers, discussion workshops, and case studies.

Key principles

The overall principles underpinning the Universal Design Guidelines for Homes in Ireland are:

- **Integrated into the neighbourhood;**

- **Easy to approach, enter and move about in;**

- **Easy to understand, use and manage; and**

- **Flexible, safe, cost effective and adaptable over time.**
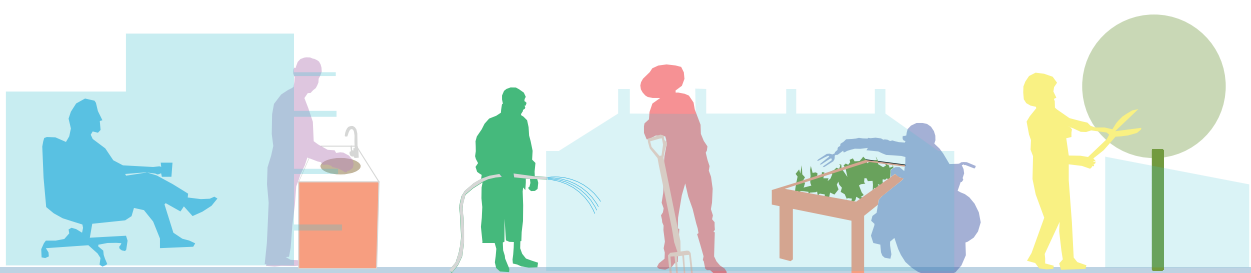
A further set of design principles to guide dementia-friendly design emerged from the research. These include:

- **Take a participatory approach to the design process, involving the person living with dementia, their family and other carers**

- **Use familiar design with recognisable features that are consistent with users' expectations**

- **Provide an environment that is easy to interpret, with good signage and multiple cues to help the person with dementia find their way around their home**

- **Provide good visual access to key areas or to important objects to remind and prompt the person with dementia when required**

- **Provide an environment that is calm, and seek to reduce noise and visual disturbance**

- **Promote well-being and prevention of injury or ill-health, with unobtrusive safety measures to protect from hazards**

- **Support a personalised environment that promotes the person's individuality and where they can feel at home**

- **Provide safe and accessible outdoor spaces which can be seen from the interior to encourage the occupant to use them**

- **Build-in the requirements of family and other caregivers**

- **Promote engagement with family and the wider community**

- **Compensate for disability**

- **Promote independence, autonomy and choice**

- **Support meaningful activities**

- **Enhance confidence and self-esteem**

- **Facilitate assistive technology**

A key message is that a person's well-being and his/her ability to master everyday activities of daily living, and their physical environment, are all closely intertwined.

Living In Place With Dementia

Understanding daily life at home for people with dementia and their families and carers is important in order to ensure their home is appropriate to their needs. A home environment that facilitates people with dementia to be in close contact with family and friends can contribute to a feeling of belonging, security, safety and continuity. The home is a place where a person with dementia can instinctively engage in leisure time activities that they personally enjoy such as watching television, reading books or newspapers, knitting, or listening to the radio. Routine activities in the home such as turning on and off the cooker, switching on and off the central heating, or adjusting the thermostat can present some difficulties, but continuing as far as possible to do these tasks is important for people with dementia in order to maintain independence and to remain involved in everyday tasks, although it may require the assistance of families and carers. Over time and as dementia progresses, the person will generally need more support to help manage their day-to-day activities.

Designing for dementia requires an understanding of the symptoms most commonly experienced by people living with dementia, and a recognition that any design solutions need to offset and/or compensate for the effects of the condition. Common symptoms include:

- **difficulty remembering things, especially recalling recent events and experiences**

- **problems with new learning**

- **impaired reasoning, judgement, and problem-solving, that is, the capacity to work things out**

- **increasing dependence on the senses**

- **increased anxiety and stress**

Other age-related changes that people living with dementia may experience include:

- **mobility difficulties leading to increased risks of falls**

- **vision and hearing loss**

- **acute sensitivity to the environment**

As the dementia advances, problems with language and communication may also arise and the individual may become disorientated in time and place, and exhibit poor or decreased judgement. The person may also manifest changes in mood, behaviour or personality. The built environment can be used to compensate for memory and cognitive loss, and to help to address behavioural changes. It can also be designed to compensate for age-related difficulties such as mobility and sensory ones.

We all face risks at home in our everyday lives, but for people with dementia, often it is their family member or caregiver who judges and makes decisions sometimes even unconsciously, about the risks and benefits confronting the person with dementia in their own home. Embracing the idea of positive risk taking encourages us to find a balance between being overprotective and respecting individual autonomy. This translates into designing dwellings from

a Universal Design approach where people with dementia are properly safeguarded, whilst at the same time providing them with an enabling environment and the opportunity to live a full life. Positive risk taking can be a useful guiding principle.

External And Internal Design Of The Dwelling

Universal Design Guidelines for homes in Ireland and the Universal Design Guidelines for Dementia Friendly Dwellings for People with Dementia, their Families and Carers set out a number of aspects for a typical home:

- **Location and approach.**

- **Entering, exiting and moving about the home.**

- **Spaces for living.**

- **Interior design.**

- **Internal services and elements within the home.**

- **Living in a neighbourhood which is familiar, safe, accessible, and distinctive and easy to navigate and find your way, are important features for a person with dementia. The research shows that Outdoor spaces can support activity and play a significant therapeutic role.**

- **Unobtrusive safety features at exit points (such as a curtain covering a door) can provide safeguards where someone is prone to wander, although safety and independence need to be carefully balanced.**

Careful design of individual rooms such as kitchens, dining rooms, bedrooms and bathrooms, for their distinct activities, can offer multiple clues to aid memory, for example, the smell of food being prepared in a kitchen, or the soft calm lights radiating from a bedroom, or coats and keys hanging in the hallway. Colour also helps people living with dementia to distinguish one room from another.

Interior design in individual rooms and spaces plays a role in compensating for difficulties associated with dementia and helping people living with dementia to remain as independent as possible. Colour contrast and choice of materials for surfaces, floors, wall and ceilings, lighting, heating and ventilation, and the acoustic environment are all important aspects which the research addresses.

Assistive technology (AT) or Ambient Assisted Living (AAL), when used ethically and cautiously, have the potential to assist in enabling people with dementia to remain in their own homes.

It is important to build homes with capacity for flexibility and with features that can easily be adapted over time, as this avoids the need for major disruptive adaptation.

Case Studies

The Research and Recommendations report includes case studies of supported housing to illustrate dementia-friendly design features that were found within these settings. The report includes a mix of case studies, one from the Republic of Ireland (Anam Cara, Glasnevin, Dublin), two from Northern Ireland (Barn Halt Cottages, Carrickfergus, Antrim and St Paul's Court, Lisburn, Co. Antrim) and one from the Netherlands (Dementia Model House, Woerden, The Netherlands).

Stakeholder Engagement

From the outset, a central component of the research was to engage with a wide range of stakeholders including people living with dementia, their families and carers. Stakeholder involvement included one-to-one or group interviews with people with dementia, their families and carers and with people drawn from a wide range of key organisations. Interviews were held with 38 individuals from a range of stakeholder organisations including: representative organisations of people living with dementia, older people and people with disabilities; government departments; local authorities, housing providers, the HSE, allied health professionals, architects, landscape architects and house builders. Following an analysis of all the data collected, a number of key themes were identified namely:

- **awareness and knowledge of dementia;**
- **perspectives on Universal Design for dementia-friendly housing;**
- **familiarity as a key principle;**
- **dementia-friendly design in different tenure types;**
- **design features to support the Universal Design of dementia friendly dwellings;**
- **planning ahead for the future;**
- **heterogeneity of people with dementia and their families;**
- **safety issues and fear of exploitation;**
- **Involving people living with dementia;**
- **sustainability and energy efficiency in people's homes;**
- **costs and cost savings;**
- **funding for adaptations; and**
- **need for community care/support services.**
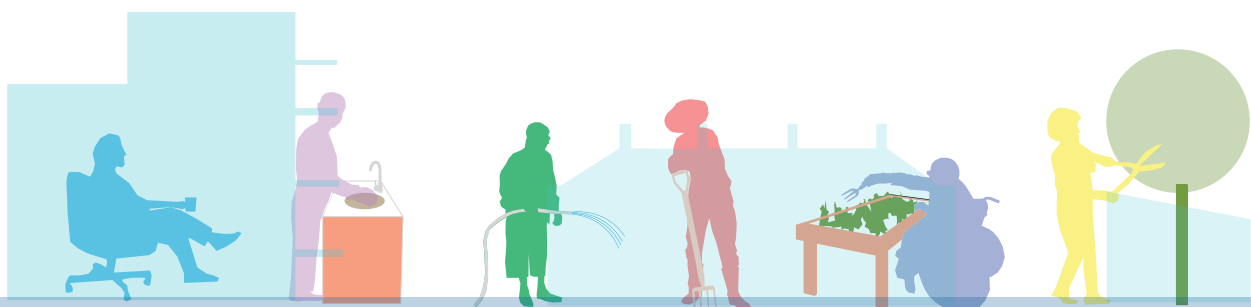
In addition, two workshops were held with stakeholders during 2013. These workshops allowed built environment professionals to engage with health service professionals and with people living with dementia, their families and carers. A sizeable proportion of stakeholders consulted during the engagement process, including many of the architects, other building design professionals and housing officers, had very little knowledge about dementia, or the kinds of supports needed to live well with dementia.

The research points to the importance of Universal Design as an approach to support and foster the creation of dementia-friendly home environments. In particular, the Research and Recommendations report endorsed the value of an iterative user-centred design process based on stakeholder participation.

Guidelines

This research underpins the Universal Design Guidelines for Dementia Friendly Dwellings for People with Dementia, their Families and Carers. The Design Guidance applies to both new build and the retrofitting of existing homes.

In terms of practice, a key recommendation arising from the research is the need for all personnel working in areas which might directly or indirectly bring them into contact with people living with dementia and their families, to know more about dementia and about how Alzheimer's disease and the related dementias affect the lives of all those experiencing the symptoms.

It is important for people with dementia living in the community, and their families, to be able to avail of housing grants and home adaptation schemes and to have access to appropriate community and home based care supports essential for enabling people with dementia to remain living at home with the support of their families and carers. Our findings would lead us to conclude that there is a need for a wide range of different housing options to be made available that meets the specific needs of people who have dementia and support them to remain in their own homes and communities for as long as possible. This is in keeping with recommendations made in the Irish National Dementia Strategy launched in December 2014.

Systematic evaluation of homes designed or retrofitted for people with dementia, their families and carers could enable better understanding of how best to design and adapt people's homes to meet the unique and complex needs of people living with dementia, their families and carers.

To download this Executive Report and the full Research & Recommendations Report please go to; www.universaldesign.ie/housing

Chapter 1: Introduction

1.1. Introduction

This report has been written by the Living with Dementia programme and TrinityHaus (Trinity College Dublin) as part of a collaborative research study undertaken on behalf of the Centre for Excellence in Universal Design at the National Disability Authority. The study was developed to underpin the development of national Guidelines. These Guidelines will be used to inform the future design of new dwellings for people living with dementia and to retrofit existing dwellings using a Universal Design approach. The Guidelines will potentially help people living with dementia to remain living at home safely and securely for as long as possible. There are several components to the research including:

i. A review of the literature: this involved undertaking an extensive review of the existing literature, which broadly addressed the following two questions: (1) What is known from the international literature about dwellings and how they can be designed and adapted to accommodate the unique and complex needs of people living with dementia and their families and carers, from a Universal Design approach? and (2) What is the current guidance for the Universal Design of Dementia Friendly Dwellings and how might it be used to inform the development of the national guidelines (commissioned by the Centre for Excellence in Universal Design at the National Disability Authority).

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ii. Stakeholder engagement: A central component of the research was to engage with a wide range of stakeholders including people living with dementia, their families and carers. The reason for this was to ensure that the research and recommendations and Universal Design Guidelines for Dementia Friendly Homes will address the actual needs of people living in the community with dementia, along with the needs of families and carers. Stakeholder involvement included one-to-one interviews with people living with dementia and their family caregivers and other individuals representing a wide range of key organisations. In addition, two stakeholder workshops were hosted where the development of this research, its recommendations and design guidance were discussed.

iii. Case studies of dwellings designed for people living with dementia, using a Universal Design approach.

A Project Steering Committee was established to guide the research (see Appendix 1).

The key findings from each of these components are presented in this report and these findings informed the development of the Universal Design Guidelines for Dementia Friendly Dwellings in Ireland.

This chapter comprises five sections. Section 1.2 provides a rationale for focusing on designing and retrofitting dwellings for people living with dementia, their families and carers. Section 1.3 focuses on the concept of Universal Design; it provides a rationale for adopting a Universal Design approach, and discusses key aspects of this approach. Section 1.4 outlines the Universal Design guidelines that currently exist in the Irish context. Section 1.5 outlines the methodology adopted with respect to the literature review, stakeholder interviews, workshops and case studies, and the challenges and limitations that arose in doing this. Finally, section 1.6 presents an outline of the structure for the rest of the report.

1.2. Rationale for the Study

Dementia is an umbrella term used to refer to a group of disorders that have common symptoms but different causes. It is an extremely costly condition and one of the leading causes of disability in later life (WHO, 2012). The most common type of dementia is Alzheimer's disease but there are several other diseases that cause different dementia syndromes. Although in a few rare cases, dementia can be reversed, most types of dementia

are progressive with no effective cure and no known treatments to halt its progression. Since the 1990s pharmacological treatments for dementia have become available, but these drugs (Cholinesterase inhibitors) address merely the symptoms and not the root cause of the illnesses. These Cholinesterase inhibitors or anti-dementia drugs work in only approximately one-third of all cases.

Non-pharmacological interventions such as Reminiscence, Cognitive Stimulation Therapy, aromatherapy, music, pet therapy, and Snoezelen to name just a few also hold much promise for supporting people living with dementia and for improving quality of life. While the latter clearly will not arrest the progression of dementia, non-pharmacological interventions are likely to provide an effective approach to lessening the impact of dementia, improving the wellbeing of people living with dementia and their family carers/caregivers and enhancing quality of life.

Designing dwellings to address the specific needs of people living with dementia, by way of landscape design, interior design and technological solutions, represents another promising approach. It is based on the premise that the built environment plays a key role in 'shaping the ways in which people lead their lives' (Imrie & Hall, 2001, p. 33) and the premise that 'there are a number of elements in the built environment including buildings, places, streets and routes which can influence health' (Institute for Public Health, 2006). Indeed, it is argued that place and health are inextricably linked and that health is determined by a range of social, environmental and economic factors wherein decisions made in these areas significantly influence health (Institute for Public Health, 2006). The built environment, however, poses a challenge for many people living with dementia, who by virtue of their cognitive and memory difficulties may no longer be able to adapt to their environment and therefore must have the latter adapted to address their specific needs.

1.3. Population ageing in Ireland and dementia

The importance of designing purpose-built living quarters and retrofitting residential long-stay care and Specialist Care Units (SCUs) for people living with dementia has been long recognised and has generated a wealth of literature (Calkins, 1987; Calkins, 2010; Day & Calkins, 2002; Day, Carreon & Stump, 2000; Judd, Phippen & Marshall, 1998; Lawton, 2001b; Pollock & Marshall, 2012; Poole, 2006; Utton, 2005; Warner, 2001). In comparison, very limited attention has been paid to the design and retro-fitting of general domestic dwellings for people living with

dementia (O'Malley & Croucher, 2005), which is surprising given that this is where the vast majority of people with dementia live.

It is estimated that there are approximately 48,000 people living with dementia in Ireland (Pierce et al., 2014). Figure 1 shows that almost two-thirds of people living with dementia in Ireland live at home in the community (Connolly et al., 2014). The prevalence of dementia in the community in Ireland is similar to most other industrialised countries.
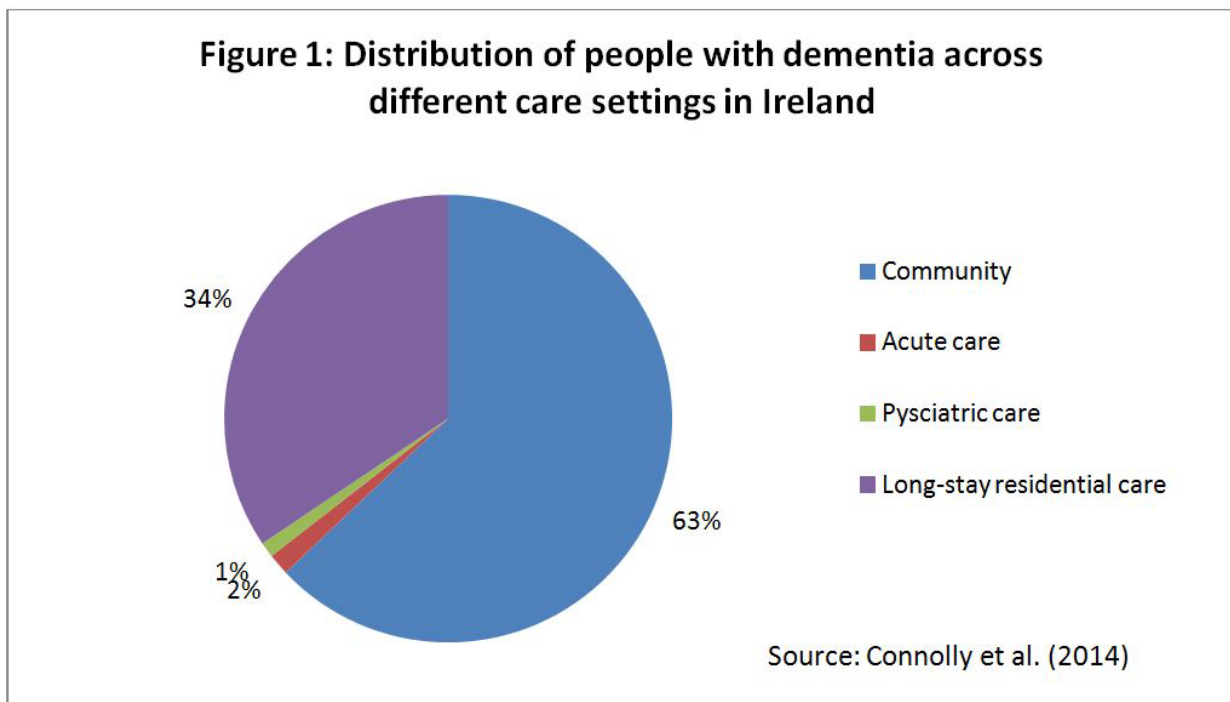
Figure 1- Distribution of people with dementia across different care settings in Ireland

Across the world, it is estimated there are approximately 44 million people with dementia and this number is set to triple by 2050 to reach 135 million (Alzheimer's Disease International, 2013). Like other countries, Ireland's population is ageing and the number of people living with dementia in Ireland is set to increase significantly over the next number of decades (Cahill, O'Shea & Pierce, 2012; Pierce, Cahill & O'Shea, 2014). If current epidemiological trends continue, it is projected that in Ireland the number of people living with dementia residing in the community is likely to double between 2011 and 2031, to reach approximately 60,000 by 2031 (see Figure 2). This will result in a growing demand for dwellings suitable for people living with dementia and their families.
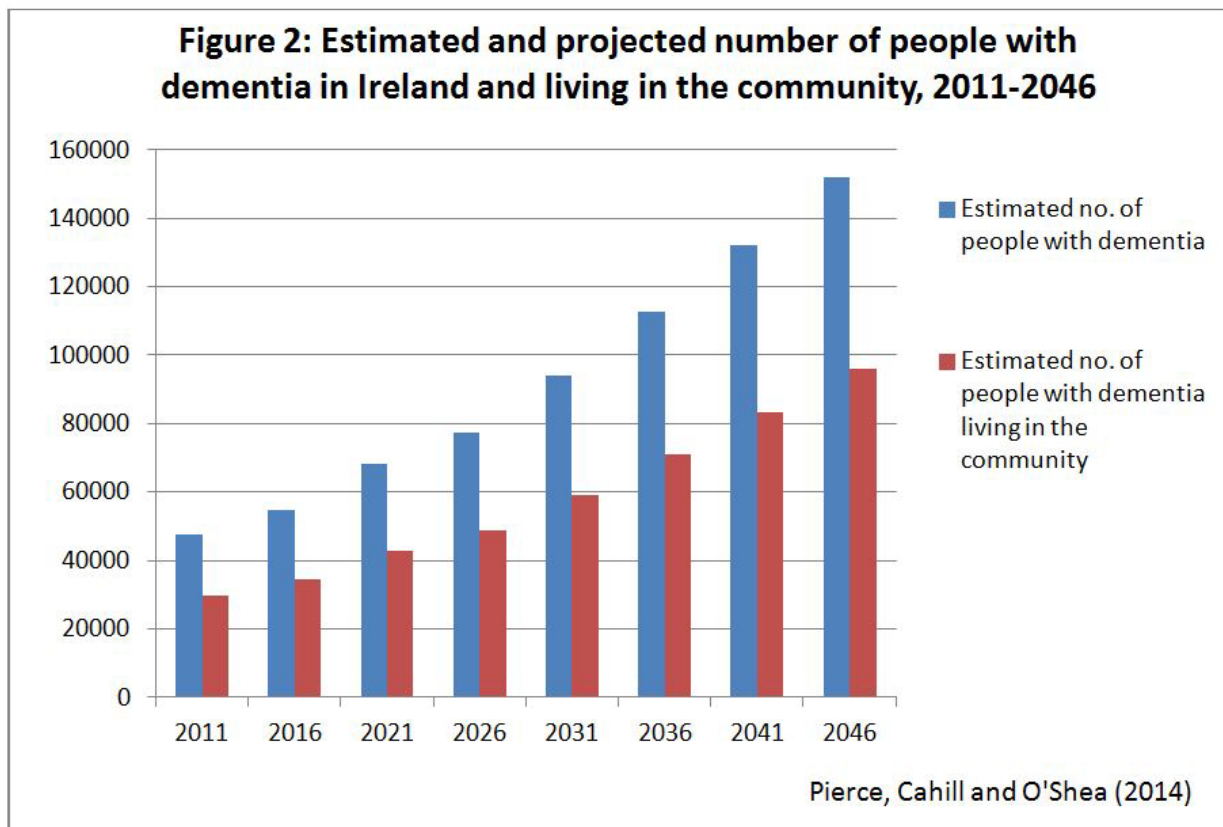
Figure 2 - Estimated and projected number of people with dementia in Ireland and living in the community, 2011 - 2046

This research is timely, given the projected growth in the number of people with dementia in Ireland, likely to be living in the community in the future and the fact that guidance relating to the design of buildings for these people has been largely overlooked.

1.4 Carers of people living with dementia in their own homes

The vast majority of care provided to people with dementia living in their own homes is by informal carers, that is care provided unpaid by family, friends and the community. Estimating the number of people involved in informal caregiving to relatives, friends or neighbours with dementia is extremely difficult as often older spouses see caring as an extension of their marital obligation and do not classify themselves as carers (Cahill, 1999).

The Census of Population 2011 (Central Statistics Office, 2012) is a key source of national data on informal carers. It defines a carer as a person (including adults and children) providing regular unpaid[1] personal help for a family member or friend with a long-term illness, health

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[1] Carers in receipt of Carers Allowance or Carers Benefit are included as unpaid carers.

problem or disability. The Census 2011 showed that there were 187,112 carers in Ireland or 4.1% of the total population. Whilst the greatest proportion of carers are in the 40-55 year age groups, about 13% are aged 65 years or over (Central Statistics Office, 2012).

A special module on carers included in the Quarterly National Household Survey (QNHS) in 2009 also provides useful data on those providing care, the extent and nature of care and the impact of caring on the life of the carer. Given the broader definition of caring (looking after or giving special help to) used in the QNHS, it is not surprising that it estimated that a higher proportion (8%) of the population were carers (Central Statistics Office, 2010). The Irish Longitudinal Study on Ageing (TILDA) has provided some helpful information on family caregivers of older people in Ireland. This study found that the majority of family caregivers of older people are spouses of the person being cared for. It found that the main carers of older people had an older profile than other carers, with close to one-fifth aged 65 years and over and the vast majority aged 50 years and over (Kamiya et al., 2012).

Whilst the Census, the QNHS and TILDA provide valuable information on carers either generally or on older people in Ireland, they do not provide any detailed information on informal carers of those diagnosed with dementia and there is no reliable and up-to-date information available in Ireland on the exact number of carers currently providing regular unpaid care and support to the estimated 30,000 people with dementia living at home in the community. O'Shea some years back (2000) estimated that there were approximately 50,000 carers looking after relatives with a dementia.

It is also difficult to extrapolate from Census or QNHS data for informal carers of those with a dementia since dementia is very different from other forms of caring (Temzstedt & Schulz, 2000). The most notable difference is that informal carers of people living with dementia are more likely to be older and in poor health themselves. Indeed the literature suggests that many have their own physical health problems and need to regularly attend their own doctor appointments (O'Shea, 2003). Caring for people with dementia differs from other forms of caregiving in that it may well extend around the clock; require on-going supervision and monitoring (due to concern's for that person's safety) and constitute hard physical labour (for example, when cleaning up after episodes of double incontinence is required). In addition, due to the nature of symptoms of dementia and challenging behaviours, caring for a person with dementia may actually erode rather than fortify what previously constituted a loving, caring

relationship. Caring for a person with dementia can place great demands and strain on family members (Bertrand et al., 2006; Ory et al, 1999; Pinquart & Sorensen, 2003; Zarit, Gaugler & Jarrott, 1999), especially if they are providing round the clock care and if they are dealing with challenging behaviours. There are not reliable and valid data on the numbers of people involved in providing informal care to relatives, neighbours or friends with dementia.

The literature suggests that a hierarchy of caring exists (Qureshi & Walker, 1989) and that family caregiving tends to be a gendered issue (Kramer & Kipnis, 1995). If a spouse is available and able then normally that person assumes the care role. In the absence of a spouse, adult children, generally older daughters, adopt the role. In the absence of daughters, the care role usually falls on daughters-in-law or sons. We suspect a similar pattern of care exists in dementia care.

Earlier literature also pointed to the weaker position in the nuclear family, relatively speaking, held by family carers. Ungerson's (1995; 1987) work for example showed that the care role often by default fell on that family member who had no legitimate excuse to exempt herself/himself from the role. In other words, adult children who were not gainfully employed in the labour market or had no children often ended up assuming the caring role. The issue about motivation to care is important as clearly in cases where the care role is taken on reluctantly or involuntarily then it may well have implications for the quality of care delivered and for the sustainability of home care.

It is common within the literature and in normal parlance to make a distinction between informal care and formal care. Formal care is care provided by workers who receive pay to provide care. In Ireland, formal care workers providing care in the home (home helps or home care assistants) are usually employed under the Home Help Service or Home Care Support Schemes, otherwise known as Home Care Packages, either by the Health Service Executive or private (for-profit or not-for-profit) home care providers. Formal care workers can also be employed directly by families. Trained dementia care workers, many of whom are engaged by the Alzheimer Society of Ireland, also provide in-home care for people with dementia. Formal care working can be a difficult and taxing job role, often with little training, and with very modest remuneration (Prince, Prina & Guerchet, 2013).

Data on the extent of formal in-home care support for people with dementia is extremely limited in Ireland (Cahill, O'Shea & Pierce, 2012), but we know that people living with

dementia receive very few in-home formal support services (Begley, 2009) meaning that the burden of care falls largely on family caregivers. In addition to formal carers, nursing and allied health professionals, typically public health nurses, community mental health nurses, occupational therapists, physiotherapists, speech and language therapists and sometimes social workers, may also visit the homes of people living with dementia and their families, but generally visits by these professionals to people living with dementia and their family caregivers are infrequent (Bobersky, 2013; Cahill, O'Shea & Pierce, 2012).

There is a dearth of literature on formal carers and the design of dwellings for people living with dementia. This is not surprising since the vast majority of care for people living with dementia in their own homes is provided by informal carers, and typically family caregivers. However, many of the environmental factors that affect informal carers, addressed in Chapter 5, also affect the ability of formal carers to provide care in the home environment.

A study undertaken by Connolly et al. (2014) estimated the overall cost of dementia in Ireland to be just over €1.69 billion per annum, 48% of which is attributable to informal care provided by family and friends to those living with dementia in the community. A further 43% is accounted for by residential long-stay care, while formal health and social care services contribute only 9% to the total costs of dementia. The findings from this study illustrate the underdeveloped nature of community care services and as a consequence the very heavy burden that falls on the family caregivers of people living with dementia in the community. This highlights the importance of including family caregivers within the scope of this research and taking account of their needs in developing the Universal Design Guidelines for Dementia Friendly Dwellings.

It has been said that for every one person diagnosed with dementia, three family members are significantly affected (Cahill, O'Shea & Pierce, 2012). Despite the significant role that family members play in supporting relatives with dementia, it is not known how many of the 30,000 community dwelling people with dementia in Ireland reside alone or how many live with family caregivers. Estimates from one London study suggest that about one-fifth of people living with dementia in the community could be living alone (Schneider et al., 2003, p. 312), whilst other studies estimate that one-third of people diagnosed with dementia live alone (Miranda-Castillo, Woods & Orrell, 2010). A French study found that about a third of people diagnosed with

dementia at memory centres live at home alone with family geographically close by. Based on these estimates, it is suspected that in Ireland between 6,000 and 10,000 of people with dementia may be living alone in their own homes with family members living nearby (Pierce, Cahill & O'Shea, 2014). Whether a person lives alone or with other family members/carers, environmental interventions will be needed by both the individual and by family members to support more independent living. Health and social care services will also be needed to address these peoples' complex needs. The inequitable and fragmented nature of health and social care services for people living with dementia in Ireland has long been recognized (O'Shea & O'Reilly, 1999; Cahill, O'Shea & Pierce, 2012).

As mentioned earlier, older family members including those co-residing with a relative with dementia may themselves have age-related health problems and/or sensory impairments and for them, environmental interventions may also be required to address their needs. When changes are made to the physical environment to address the needs of a person with one type of difficulty, this may pose problems for others with other types of impairment (Barnes, 2011). This is particularly relevant to designing for people with dementia who are residing with other family members/carers. For example changing the layout of someone's home to make it accessible for an older woman who because of a stroke or severe arthritis uses a wheelchair may pose a problem for her spouse with dementia. Installing push buttons to open doors, including the hall door, may be problematic for a person with dementia for whom exit and entry points are more accessible or indeed when the adapted dwellings becomes unrecognisable and causes much confusion and some distress. Thus the needs of the various occupants are likely to have a bearing on the design or adaptation of their home where a person with dementia lives with other family members.

1.5 Universal Design to Promote Ageing in Place

Another impetus for developing Universal Design Guidelines for Dementia Friendly Dwellings is that most older people express the wish to avoid moving into special care settings (Garavan, Winder & McGee, 2001; O'Hanlon et al., 2005) and arguably the vast majority of people living with dementia supported by their families, also want to remain living independently at home (Goldsmith, 1996). People with dementia living in nursing homes are known to express personal loss and to miss home greatly (Chaudhury, 2002; Cahill & Diaz-Ponce, 2011). The significance that people living with dementia attach to their home and its locale is thus

important. In addition, people living with dementia often have difficulty perceiving, processing and adapting to new environments such as nursing homes while they continue to hold strong and long embedded memories of home (Zeisel, 2006). Because of memory problems, ageing in place is particularly apt for people living with dementia as it allows them to spend as much of the rest of their life as possible in a place which they have been familiar with for a long time (DSDC Stirling, 2010).

The long stated objective of government policy for older people and for people living with dementia is to facilitate them to remain in their own home for as long as possible and practicable, and to delay admission to residential long-stay care. The Care of the Aged report of 1968 argued that the provision of suitable housing was one of the most important factors in enabling older people to continue to live in the community (Inter-departmental Committee on the Care of the Aged, 1968). The Years Ahead report in 1988 endorsed the position that proper housing is crucial to enable older people to live a dignified and reasonably independent life at home for as long as they wish (Working Party on Services for the Elderly, 1998). One of the four national goals of the recently launched National Positive Ageing Strategy is to 'enable people to age with confidence, security and dignity in their own homes and communities for as long as possible' (Department of Health, 2013, p. 19). One of the objectives (3.2) under this goal is to facilitate older people to live in well-maintained, affordable, safe and secure homes, which are suitable to their physical and social needs. Universal Design has been identified as one of the priority areas for action to achieve this objective. Others include Lifetime adaptable housing, alternative housing options (i.e. social housing, sheltered housing; retirement villages), assistive technology, and linkages between housing and health. The National Positive Ageing Strategy also has an objective to support through Universal Design the design and development of age friendly public spaces, transport and buildings.

Likewise, the 'National Housing Strategy for People with a Disability 2011-2016' sets out a number of strategic aims including "equality of access for people with a disability to the full range of housing options" and "To support people with a disability to live independently in their own houses and communities" (DECLG & DoH, 2012). It states that 'technology can assist people with dementia, in association with safe and well-designed living spaces, to live as independently as possible' (p. 95). The strategy supports the Programme for Government commitment to promote and support universal design, particularly to ensure accessible housing. In line with this commitment, a key measure of the National Implementation Framework (DECLG & DoH,2012)

is that 'an examination of 'lifetime housing policy' and universal design will be undertaken, which will consider, inter alia, relevant economic implications and review existing international lifetime homes standards and best practice (p. 24). It is widely recognised that living in a safe, adapted and manageable home can improve health, reduce the need for support services, and increase independence. In Sweden and Norway, social policy on dementia is underpinned by the principle of "normalization", that is, even if you have dementia, you should live a normal life, similar to that of all citizens in the community (Eriksson, 2010; Norwegian Ministry of Health and Care Services, 2008). The importance of safeguarding the rights and dignity of people with dementia has also been emphasised at European Union level (European Commission, 2009).

Cost is a fundamental consideration in the building of new dwellings and the retrofitting of pre-existing ones. Undoubtedly, some would argue that building new dwellings for people living with dementia and their families and carers using a Universal Design approach is costly. However, this view needs to be challenged, as retrofitting is expensive and significant long-term savings can be gained from building homes of different sizes, which from the outset are designed to accommodate and support people of different ages, abilities and disabilities, although these savings are not necessarily made at the building stage (Hemingway, 2011). As well as improving how the person with dementia and their family lives, designing dwellings to meet the person's needs and support them to remain in their own home for longer is of great importance for public expenditure, since long-stay care is a very costly form of care (Connolly et al., 2014) and as already mentioned is not the care option that most older people or indeed their caregivers favour.

The expressed wish of people with dementia to remain living at home, the significant role that families play in caring for relatives with dementia, the high cost of residential care, the likely doubling of the population of people with dementia over the next 20 years and current government policy are all justifications for the idea that domestic dwellings might be conceived, designed and constructed so that the desires, capacities and needs of people with dementia living in their own homes and those of their families can be met. The opportunities thus presented highlight the importance of focusing on Universal Design for Dementia Friendly Dwellings to enable people with dementia to live at home for as long as possible with the support of their family caregivers.

1.6. **A** Universal Design Approach

This section focuses specifically on the use of a Universal Design approach in the design of dwellings for people living with dementia and their families and carers. The term Universal Design was first coined by Mace (1998) to refer to "the design of products and environments to be usable by all people, to the greatest extent possible, without the need for adaptation or specialist design" (p. 21-28). While there is no single agreed definition of Universal Design, most experts draw on Mace's conceptualisation.

In Ireland, the Centre for Excellence in Universal Design at the National Disability Authority refers to Universal Design as "the design and composition of an environment so that it can be accessed, understood and used to the greatest extent possible by all people, regardless of age, size, ability or disability".[2] In a similar vein, the definition of Universal Design adopted by the United Nations in the Convention on the Rights of Persons with Disabilities (UNCRPD) refers to "environments … to be usable by people, to the greatest extent possible, without the need for adaptation or specialized design" (United Nations, 2006). This definition goes on to caution that "Universal Design shall not exclude assistive devices for particular groups of persons with disabilities where this is needed". Several other terms such as 'Inclusive Design' and 'Design for All' have emerged in recent years and are similar to Universal Design. They all are approaches to design, that result in products, services and built environments that are easier for everyone to use.

A Universal Design approach results in dwellings that are easier for everyone to use. In contrast, it is widely acknowledged that poorly designed environments cause difficulties for large sections of the population at different stages of the life course, particularly older people and people with physical, sensory and cognitive impairments. In recognition of possible exclusionary design, the UN Convention on the Rights of Persons with Disabilities (UNCRPD, Article 4 outlining General Obligations) states that:

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[2] The definition adopted by the CEUD draws on the Disability Act 2005, which defines Universal Design as meaning: "the design and composition of an environment so that it may be accessed, understood and used to the greatest extent possible, in the most independent and natural manner possible, in the widest possible range of situations, and without the need for adaptation, modification, assistive devices or specialised solutions, by persons of any age or size or having any particular physical, sensory, mental health or intellectual ability or disability." and in relation to electronic devices, as meaning "any electronics-based process of creating, products, services or systems so that they may be used by any person".

"States Parties undertake to ensure and promote the full realization of all human rights
and fundamental freedoms for all persons with disabilities without discrimination of any
kind on the basis of disability. To this end, States Parties undertake:

(f) to undertake or promote research and development of universally designed goods,
services, equipment and facilities … which should require the minimum possible
adaptation and the least cost to meet the specific needs of a person with disabilities, to
promote their availability and use, and to promote Universal Design in the
development. (United Nations, 2006)

The UNCRPD is designed in an international law context and has, according to Ostroff (2010),
contributed to the significance that Universal Design has gained internationally. The UNCRPD
sets out the duties of countries to protect the human rights of people with disabilities, including
those with dementia. It is said to be legally binding on any country that ratifies it. At the time of
writing, the UNCRPD has not been ratified by the Irish government. Nevertheless, the
UNCRPD substantiates the adoption of a Universal Design approach in this study.

The National Disability Act 2005, as well as establishing the statutory right for all people to
fully participate in Irish society, enshrines the principle of Universal Design and thus insists on
environments designed to be accessed, understood and used regardless of age, size, ability or
disability (Office of the Attorney General, 2005). Designing dwellings for people living with
dementia from a Universal Design approach is consistent with this legislation.

Despite this legislation and regulatory developments in the form of Part M of the Building
Regulations, in addressing disablement, the emphasis has largely been placed on physical
impairment, an issue that is not unique to Ireland (Crews & Zavotka, 2006). As a consequence,
the needs of people with cognitive impairments and dementia have been largely overlooked. By
focusing on Universal Design for Dementia Friendly Dwelling the present study goes some way
to addressing this omission.

Inevitably, the emergence of Universal Design has generated considerable debates, with some
key issues having relevance to the design of dwellings for people living with dementia and their
families and carers. Questions that arise include:

(i)   What is the quality of the housing stock in Ireland?

(ii)   What place does specialised design have in Universal Design?

(iii)   How can architects be educated about the importance of Universal Design?

(iv)   How can the end-users be included in the design process?

1.7 Housing stock and Universal Design

The concept of Universal Design includes the idea of creating environments that are usable, understandable and accessible for all people regardless of age, size, ability or disability at the outset rather than having to add or adapt features at a later date. The age profile of the Irish housing stock is said to be relatively favourable by international standards (Watson & Williams, 2003). According to the Census of Population, 28% of the housing stock in 2011 was built between 2000 and 2011. The Census also shows that in 2011, almost three-quarters (72%) of all domestic dwellings were over 10 years old with almost a third (32%) were 40 years or older.

As building regulations were not introduced in Ireland until 1991, this means many dwellings will not have been originally built according to the regulations that control energy use, ventilation, fire safety, access and other important issues around the construction of quality dwellings. Meanwhile, Part M of the Building Regulations, which since 2010 provides guidance and standards in relation to access and use, was first introduced in 2000[3]. As a result, only newer dwellings will have been built to meet higher building standards in relation to access and use, fire safety, construction quality such as insulation and damp-proofing, or internal environmental conditions related to sound, hygiene or ventilation. However, older people are more likely to occupy older dwellings and the housing stock of older people tends to be poorer than that of the population as a whole and older people living alone are less likely to have central heating and hot water and are more likely to live in conditions prone to dampness and with poorer sanitation facilities (Norris & Winston, 2008).

Almost half of all older people live in houses built before 1960 and these older houses are more likely to lack an efficient central heating system and have problems with leaks or dampness (Goodman, et al., 2011). This evidence is important because a person's physical environment can have an impact on their health and well-being (Braubach et al., 2011) and serves to highlight the significance of improving housing conditions. Research from the UK on the 'costs of poor housing' (Roys et al., 2010) refers to a growing body of evidence that

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[3]These were introduced in 2000 as Access for people with Disabilities and revised in 2010 as Access and Use.

connects adverse health effects with housing conditions, which includes: dampness, the effects of living in cold conditions, household accidents, noise, insecurity, overcrowding and fire safety. This research used the UK Government's 'Housing Health and Safety Rating System' (HHSRS) (ODPM, 2006) which categorises four classes of hazards ranging from minor health outcomes such; as regular skin irritations, occasional mild pneumonia, or regular coughs and colds (Class IV); to major outcomes such as death, permanent paralysis, or severe burn injuries (Class 1). Using this rating system, Roys et al. (2010) calculated that Class I hazards in British homes are costing the British National Health System (NHS) in excess of £600 million per year and that the total cost to British society may be greater than £1.5 billion annually. While this research is based in the UK it nevertheless illustrates the impact of housing conditions on human health and well-being.

Furthermore, given that most people living with dementia are over 65 years of age, that their partners and siblings and some adult children caring for them are likely to be older too, and that a high proportion of housing is over 30 years old, it is also reasonable to assume that a limited number of people living with dementia and their older family caregivers are living in homes that are fully usable and accessible. As a consequence, improving housing conditions, adaptations or assistive technology (or both) are extremely important and may be necessary for making dwellings suitable for people living with dementia and for their family caregivers.

1.8 The place of specialised design in Universal Design

Universal Design aims to reduce the need for special provision. However, it is not about providing a "one-size-fits-all'. Lawton (2001a, p. 7, 12) argues that although human needs are universal and that it is "possible to pursue a universally relevant procedure as the design process proceeds," it is unreasonable to assume that "every design decision will result in optimum usability for every person" (Lawton, 2001a). Accordingly, Universal Design, rather than being a "one size fits all approach", can be viewed as knowing the diverse range of functional needs and at the very start building this range into the design. Buildings can be adjusted then to suit the specific individual needs as required. This approach will help to achieve what Lawton (2001a) refers to as "the universal goal of representing every common need in the design, if not by the same solution in every case" (p. 7, 13) and thereby help to close the gap between Universal Design and specialised design.

Jon Sanford, an author of the original Universal Design principles, argues that while Universal Design is applicable to all people, it has a particularly important role in supporting people with disabilities and older people (2012). He believes that one of the real advantages of Universal Design is that it can accommodate change over time. He also argues that while it cannot meet the needs of every individual user with specific needs it creates a high supportive baseline which can then be adapted for specialised needs.

> "This is not to say that Universal Design is a panacea that will forever obviate the need for specialized design. Rather, it creates a higher, more inclusive baseline from which rehabilitation can operate. As a result, it may eliminate the need for specialized design for some or reduce the need for other" (Sanford, 2012, p. xii)

This way of thinking about Universal Design is useful in the context of dementia friendly dwellings and provides a conceptual framework for balancing the needs of typical dwelling occupants with the more specific needs of a person with dementia who may also live in the house. Figure 3 illustrates this framework, where standard design only provides for a limited proportion of people in society, and Universal Design provides a higher more inclusive baseline from which specialised care, personalisation, or adaptations to suit individual preferences can take place.
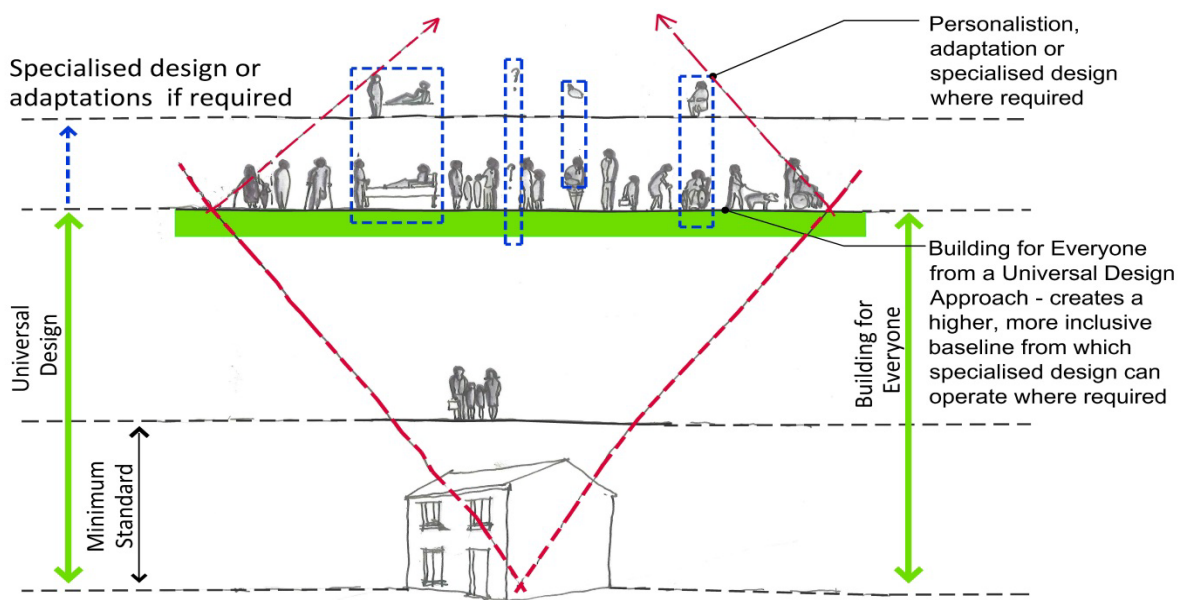
Figure 3 – Universal Design creates a higher, more inclusive design baseline

1.9 Universal Design as a Person-centred Process

An understanding of Universal Design as a user-centred process is extremely useful here. Universal Design can be understood as "a process that enables and empowers a diverse population by improving human performance, health and wellness, and social participation." A criticism of Universal Design has been that it does not pay enough attention to the inclusion of users in all phases of the design process. Sandhu states that "people appear to be an abstraction in the UD process" (2011. p. 44.2), whilst Krauss argues that one of the differences between Universal Design and 'design for all' (DfA), as applied in Germany, is that Universal Design is more end product focused, while DfA is process orientated (Krauss, 2011). These criticisms point to the importance of including the end-users in the design process. This will ensure not only a better understanding of their needs but is also likely to encourage the resident of the dwelling to have a better sense of ownership.

Steinfeld and Maisel (2012) contend that design participation needs to be a critical part of Universal Design. They suggest that efforts should be made in every design project to include representatives of end users. It could be argued that housing is one of the most important areas for design participation. Cooper Marcus argues that one of the most serious constraints facing housing designers is the lack of input from the very people who are destined to live in the housing once it is completed (Cooper Marcus & Sarkissian, 1986). Orpwood (2009), discussing the design of assistive technology, laments the fact that many design solutions are technology led. He argues for designers to have an intimate knowledge about not only the issues that face users when they interact with a technology, but also how they might react to potential solutions (Orpwood, 2009). He believes that because of the complexity of human behaviour and the way people interact with technology, it is impossible for designers to work in isolation from the end user (Orpwood, 2009). Because of the challenges raised by involving people living with dementia in the Universal Design process, there is a need to employ sensitive and ethical approaches when working with them (Orpwood, 2009).

1.10 Universal Design and Sustainability

The UN argues for "the integration of the three components of sustainable development - economic development, social development and environmental protection – as interdependent and mutually reinforcing pillars." (United Nations, 2005, p. 12). The development of low energy, sustainable and inclusive housing is now a major part of this sustainable development and the

design of neighbourhoods and cities which must incorporate a variety of perspectives including social, technical, political and economic issues (Edwards & Turrent, 2000). In terms of environmental performance, the residential sector consumes a substantial amount of energy and other natural resources and emits large volumes of CO_2. The 2006 figures for Ireland show that the residential sector used 23% of the country's final energy (up 32% from 1990) and was responsible for 25% of Ireland's CO_2 emissions (approx. 8.1 tonnes of CO_2 per household) (SEAI, 2008). Housing is therefore a critical component in the sustainable design of the built environment.

Universal Design of dementia friendly dwellings has the potential to contribute significantly to the sustainability of the housing stock. It can be seen as a key part of the social sustainability component of sustainable development as it "helps the full inclusion and participation in family and community life" (Duncan, 2007, p. 27). Duncan contends that Universally Designed dwellings also align with environmental sustainability. Universal designed dwellings minimise the need for modifications to an existing dwelling that may otherwise be required to make a home functional and accessible by a person with a disability. In this regard, sustainability is one of the overarching principles of Lifetime Homes where it is argued that the long-term accessibility, flexibility and adaptability of a Lifetime Home will help maintain the usability and popularity of the home and thus support the creation and maintenance of thriving communities (Goodman & Habinteg Housing Association, 2011). This relationship is also identified in the Irish Government document 'Guidelines for Planning Authorities on Sustainable Residential Development in Urban Areas", as the following statement shows;

> "sustainable design and Universal Design are inextricably linked and sustainable design when incorporated from the early stage of planning integrated neighbourhoods, will reduce the need for costly and wasteful retrofits over the medium to long term"(DEHLG, 2009a, p5).

Various international standards have been developed to guide and evaluate housing developments in relation to sustainability, such as the US based 'LEED Homes' (USGBC, 2013), or the UK based 'Code for Sustainable Homes' (BREEAM, 2013). This UK code is interesting as it adopts an integrated approach to sustainable design and in doing so incorporates a wide range of criteria including: Energy and CO2 emissions, Water, Materials, Surface Water Run-off, Waste, Pollution, Health and Wellbeing, Management, and finally Ecology. Each category

comprises a number of points and the overall housing scheme is evaluated based on the sum total of points awarded for each category. Of these nine categories, only Pollution, Management, and Ecology are not mandatory. The Health and Wellbeing category contains four sub-categories including; Daylighting, Sound Insulation, Private Space and Lifetime Homes.

The Lifetime Homes concept, which was developed in the 1990s by the Habinteg Housing Association, the Helen Hamlyn Foundation and the Joseph Rowntree Foundation, contains 16 accessible and inclusive criteria ranging from car parking, internal circulation, and room sizes, to window design, sockets and lighting controls (Goodman & Habinteg Housing Association, 2011). The inclusion of health and wellbeing, particularly the Lifetime Homes concept, ensures a more integrated approach towards sustainable housing incorporating the social component of sustainable development.

In Ireland over the last decade, a number of national level government documents and guidelines have been delivered which seek to address the issue of sustainable housing. The 2007 document 'Delivering homes sustaining communities national housing – Statement on housing' (DEHLG, 2009) focuses on the importance of housing and states that "Sustainability involves the construction of homes that are structurally sound, energy efficient, environmentally friendly and adaptable over time to changing household needs." This was followed by other guidelines which placed housing in the broader context of planning and urban design (DEHLG, 2009a; DEHLG, 2009b) where each emphasises the critical role of housing in the creation of a sustainable community.

These guidelines are relevant to the sustainability of dementia friendly dwellings from a Universal Design approach. It is unnecessary however to address all the sustainability issues related to housing in this report, as they are addressed in detail in the documents listed above. Nevertheless, it is worth revisiting some of the sustainable design criteria with a view to looking at them through a dementia lens. Those that warrant closer inspection include the location of dwellings, the maintenance of a high quality environment, design for flexibility, daylighting, thermal insulation, space heating and controls. The criteria which are relevant to the Universal Design of Dementia Friendly Dwellings will be addressed in Chapter 5. Issues relating to sustainability were also raised in the stakeholder interviews and these will be presented in Chapter 7 of this report.

1.11 Universal Design and Life Cycle Costs

As mentioned earlier, cost is a fundamental consideration in the building of new dwellings and the retrofitting of pre-existing dwellings. Life cycle costing is a method of economic analysis that can be used to determine the costs related to building, operating, and maintaining a dwelling over a defined period of time. The construction costs associated with the Universal Design of Dementia Friendly Dwellings are addressed in Chapter 5. Another cost issue to consider is that dwellings designed from a Universal Design approach for people living with dementia and their families and carers will, by improving how the person with dementia and their family lives, support them to remain in their own home for longer and thereby reduce the need for admission to residential long-stay care. This is of great importance for public expenditure, since long-stay care is a very costly form of care (Connolly et al., 2014) and as already mentioned is not the care option favoured by the majority of older people or indeed their families and carers.

1.12 Universal Design Guidelines in Ireland

The Centre of Excellence in Universal Design at the National Disability Authority is dedicated to enabling the design of environments that can be accessed, understood and used regardless of age, size, ability or disability. The production of guidelines is one way in which Centre for Excellence in Universal Design at the National Disability Authority promotes the concept, philosophy and principles of Universal Design and encourages developers, designers, builders and building managers to be innovative and think creatively about solutions that meet the needs of all building users.

In 2012 the Centre for Excellence in Universal Design at the National Disability Authority produced 'Buildings for Everyone: A Universal Design Approach', a series of ten booklets that provide comprehensive best practice guidance on how to design, build and manage buildings and spaces so that they can be readily accessed and used by everyone, regardless of age, size ability or disability.

Figure 4 – Centre for Excellence in Universal Design at the National Disability Authority publications: *Buildings for Everyone: A Universal Design Approach* **and** *Universal Design Guidelines for Homes in Ireland*

The booklets provide design guidance for the built environment at different levels including the design of streets, facilities, individual buildings, and building services. The series covers the topics of the External Environment, Entrances and Horizontal Circulation, Vertical Circulation, Internal Environment and Services, Sanitary Facilities, Facilities, and Building Types. This series also refers to building management and planning policy, and therefore provides a good overview of the Universal Design of the built environment.

The Centre for Excellence in Universal Design produced draft guidelines titled 'Universal Design Guidelines for Homes in Ireland' to inform policy and practice in relation to new home design. It is intended that these guidelines will inform national policy and be used in practice by all stakeholders – those who commission, design, build, provide and occupy homes. The intention is that if new homes or alterations to existing ones are built to a Universal Design standard, then they will be suitable for the needs of people regardless of age, size, ability or disability. This will facilitate the provision of dwellings that can readily meet the changing requirements of people living in them over time, facilitating people remaining in their own homes and communities as they get older or experience mobility and/or health difficulties.

The current study builds on such earlier works and underpins the development of new national guidelines. Published by the Centre for Excellence in Universal Design and titled 'Universal Design Approach for Dementia Friendly Dwellings, these guidelines complement the "Building for Everyone: A Universal Design Approach" and "Universal Design Guidelines for Homes in Ireland" publications as well as current Building Regulations that apply to domestic dwellings.

Independent of this current study, there is a separate study, overseen by the Working Group on Housing Design and Adaptations to Promote Independent Living for People with Severe and Enduring Mental Health Problems, of guidelines, intended to underpin the future design and adaptations of dwellings for people with severe and enduring mental health problems, with a particular focus on people living with schizophrenia.

1.13 Methodology

The section to follow now outlines the methods used to undertake the stated components of this research study.

Literature review: The literature review followed established methods (Arksey & O'Malley, 2005). In order to identify primary studies[4], reviews and guidance documents suitable for answering the key research question, the strategy adopted involved searching for research evidence via diverse sources. These included:

- electronic databases and search engines
- hand-searching of key journals
- existing networks, relevant organisations and conferences
- reference lists

The computer-based search performed to identify literature published between 1980 and 2013, included searches of the following electronic databases: Cochrane Review, Social Sciences Index, Sociological abstracts, PsycInfo and Scopus. Searching of key individual journals (e.g. Universal Design, Dementia, Built Environment) was also undertaken. The review involved

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[4] Both published and unpublished.

searches of Google, Google Scholar and other similar online search engines. It included a review of literature from the TCD and the DSIDC libraries and other online databases. Searches were made of publications from the following existing networks, research centres and other relevant organisations:

- Dementia Services and Development Centre, University of Stirling
- Thomas Pocklington Trust
- Bradford Dementia Group
- Hammond Care
- Helen Hamlyn Centre, Royal College of Art, London
- Housing LIN

The search was supplemented by manual searching of reference lists in the publications identified and restricted to publications in the English language. Foreign language material was excluded because of the cost and time involved in translating material. However, every effort was made to include literature from as many different countries as possible.

Stakeholder interviews: A list of key organisations to which the Universal Design of Dementia Friendly Dwellings is of relevance was drawn up by the research team in consultation with the Centre for Excellence in Universal Design at the National Disability Authority and the Steering Committee. A key contact person in each organisation was identified and the organisation was invited to participate in an interview to discuss their views on the Universal Design of Dementia Friendly Dwelling. People living with dementia and their family caregivers were also invited to participate in a stakeholder interview. In total, interviews were conducted with 39 individuals representing a wide range of stakeholder organisations.

Stakeholder workshops: Professionals with an interest in Universal Design and Dementia Friendly Dwellings, many of whom had participated in the one-to-one stakeholder interviews, were invited to attend the two workshops. People living with dementia and their families and carers were also invited to attend. Further details about the organisation and findings emerging from these two workshops are detailed in chapter 7 of this report.

Case studies: Case studies were identified through web-based searches, a review of published case study literature and consultation with experts in the areas of Universal Design and Dementia in a range of countries including Ireland, the Netherlands, England, Northern Ireland and Australia.

The literature reviewed proved to be wide-ranging. While the focus of this study is on the design of dwellings for people living with dementia, their families and carers in the community from a Universal Design approach, it necessarily draws on literature covering the range of living environments for people living with dementia. Much of the relevant research on the design of buildings for people living with dementia has been undertaken in residential care settings and its application to the home environment has rarely been tested. Research on dwellings for people living with dementia is extremely limited. Because of the limited research on the dwellings of people living with dementia, the literature reviewed for this study covers the broader range of published works on the living environments for people living with dementia. Because of the challenges associated with conducting research on the topic (Gitlin, 2003; van Hoof et al., 2010a, 2010b), the findings presented in Chapter 5 are based on findings from research studies and from expert opinion. The findings from research studies include those from randomised controlled trials (RCT), often regarded as the ideal/Gold Standard (Cantley, 2007) but rarely appropriate for research on the built environment and its role in supporting people living with dementia (Calkins, 2009) for two main reasons. First, it is virtually impossible to randomly assign individuals to different settings or to different environmental interventions. Second, it is difficult to control for cross-site variations and studies are often conducted without a control, i.e. without a comparison group or without removing the intervention to return to the baseline condition (Calkins, 2009).

Arguably, such challenges are even more pronounced in the home setting. Other findings from studies aimed at understanding the impact of design on people living with dementia are based on expert observation of behaviours of people living with dementia and single-site case studies, which can provide a depth of qualitative analysis but there are questions surrounding generalisability. Despite the available research often this evidence is inconclusive and offers little certainty (Calkins, 2009; Fleming & Purandare, 2010). Fleming and Purandare (2010) conclude

that findings from existing studies support the previously published 'consensus of views' on principles for designing facilities for people living with dementia[5] (Marshall, 2001).

Recommendations regarding the design of or retrofitting of the physical environment for people living with dementia are often based on expert opinion or anecdotal evidence (Day, Carreon & Stump, 2000) and whilst not proven may still be helpful (Smith et al., 2004). Furthermore, experts like Day and colleagues (2000, p. 397) are of the view that 'not all design guidance requires empirical research findings to justify its recommendations'. They qualify this by arguing that empirical research is needed to resolve situations in which conflicting design recommendations are offered, when the effectiveness of recommended design resolutions are unknown, or when design recommendations have major or controversial impacts for quality of life or cost (Day, Carreon & Stump, 2000). Torrington and Tregenza (2007, p. 82) argue that when assessing whether to endorse a particular feature, it may not be apt to ask 'Is the benefits of this proven?' Instead, it may be more appropriate to consider 'Does the probable benefit outweigh the disadvantages of implementation?' In general Torrington and Tregenza (2007) have found that they err on the side of inclusion.

1.14 Scope of the Study

From a Universal Design approach, this study extends to both new build[6] and the retrofitting of existing dwellings[7]. Retrofitting can involve small-scale adaptations such as adjusting lighting, installing handrails, ramps or hoists, widening doorways, or large scale structural modifications such as building extensions or altering access into or around a dwelling.

The research covers the location and approach to the dwelling, the entrance into the house and movement around it, different living spaces within the house, internal services, interior design and technology. Therefore, the research reported here covers both the exterior and interior of the dwelling and the various elements within it.

This report covers people living with dementia, their families and carers (informal and formal carers). It addresses dwellings for an individual with dementia who lives alone but may have

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[5] See Chapter 3 for a more detailed account of same.
[6] That is, the construction of a new building.
[7] This involves the introduction of new features or the adaptation or extension of an existing dwelling to render it suitable for the needs of its current occupants.

family members living close by and formal caregivers visiting and providing services, and dwellings where the person with dementia is living with family members or carers.

The guidelines based on this research study are relevant for different tenure types. About two-thirds of people living with dementia in Ireland are living in the community (Cahill, O'Shea & Pierce, 2012; Connolly et al., 2014). While it is not known where in the community these people live, it is reasonable to assume that, like people with other disabilities (Fennell et al., 2010) and older people in general (Norris & Winston, 2008), the majority live in owner occupied homes. Although exact numbers are unknown, some small groups of people with dementia live in housing schemes provided by either local authorities or voluntary and co-operative housing associations or private organizations. Of interest here also are those that specialize in housing for older people and people with intellectual disabilities. In Ireland very few housing schemes have been developed to provide accommodation specifically for people living with dementia (Convery, 2014). People living with dementia also undoubtedly reside in private or local authority rented accommodation. Adopting a Universal Design approach for dementia friendly dwellings is important in all tenure types (Cox, 2006).

1.15 Report Structure

This report comprises six chapters as follows;

Chapter 2 presents the key theoretical frameworks within which Universal Design for dementia friendly homes can be placed. 'Universal Design Guidelines for Homes in Ireland'

Chapter 3 presents the goals and principles of Universal Design. Over the years, various sets of design goals and dementia friendly design approaches have been developed. These have largely been developed for the design of long stay residential care environments. Chapter 3 considers how relevant these approaches are for the design of domestic dwellings for people living with dementia, their families and carers. The chapter then goes on to examine these goals and design approaches in the context of Universal Design to determine what specific design issues for people living with dementia need to be considered to inform the Universal Design approach

Chapter 4 focuses on people living with dementia and their families and carers within the home environment. In keeping with Davis et al. (2009) who propose that an understanding of the 'lived experiences' of people with dementia and their families in everyday life is important in order to create appropriate physical environments, this chapter focuses on the subjective experiences of these people. In addition to an appreciation of the 'lived experiences' of people with dementia and their families in the home, an understanding of the symptoms most commonly associated with dementia is also required and this is next addressed in this chapter. Where relevant, reference is also made to the experience of formal carers providing care in the home to people with dementia.

Chapter 5 presents a comprehensive review of the literature on the design, building and adaptation/retrofitting of dwellings for people living with dementia and their carers (both formal and informal). For the purposes of consistency, the presentation of the findings largely follows the headings in the series of booklets titled "Building for Everyone: A Universal Design Approach". Where applicable, issues relating to sustainability are incorporated throughout this chapter. Some construction costs associated with the Universal Design of Dementia Friendly Dwellings are also outlined.

Chapter 6 presents selected case studies of dementia friendly design used in several housing with care schemes in Ireland and in a dementia model house in the Netherlands to highlight some of the most salient design features for the Universal Design of dementia friendly dwellings. Although we came across many dementia friendly housing with care schemes, we are unaware of any dementia friendly dwellings in other countries, despite extensive searchers across a range of European countries including Scandinavian countries or in the US and Australia.

Chapter 7 presents the main findings from the stakeholder engagement process including the interviews and the workshops.

Chapter 8 draws together the final conclusions and a set of recommendations for the Universal Design of new build and existing dwellings for people living with dementia, their families and carers.

Chapter 2: DISABLING AND ENABLING ENVIRONMENTS

2.1. Introduction

The introduction to this report drew attention to the concept of Universal Design and the role that the built environment plays in shaping peoples' lives. Universal Design seeks to 'design out' barriers and to enable and support a wider spectrum of society, through accessible, usable and understandable environments. In a similar manner, dementia friendly design from a Universal Design approach aims to build on the retained abilities people living with dementia still have and to use the environment as a therapeutic tool to provide supportive independent and sensitive living.

A Universal Design approach to dementia friendly environments draws on theories relating to the interaction between people and the environment. A useful paradigm for understanding such interaction is seen in the model developed by the Institute of Public Health in Ireland which demonstrates ways at both macro and micro levels in which various components of the environment impact on physical, mental and social health (Institute of Public Health in Ireland, 2006). Such theories can be helpful in facilitating a change in thinking away from disabling to enabling environments.

This chapter presents some of the key frameworks within which Universal Design of dementia friendly design can be situated. It first looks at how person-environment theories have helped

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to shift the focus away from the impairment as the cause of disability, to the environment as a major cause. It then describes how health and disability are defined by the World Health Organization (WHO, 2001) through the 'International Classification of Functioning, Disability and Health' (ICF) and shows how this definition helps to reinforce this shift away from a belief that the individual is the source of the problem to a view that the environment itself can contribute significantly to the individual's problems. The ICF focuses on the full person and stresses the need to support a person's ability to carry out activities in order to maintain functioning and social participation.

2.2. Person–Activity–Environment Relationship

Lawton, a renowned US Behavioural Psychologist (who has made a major contribution to Architecture, Gerontology and Dementia), contended that any model for optimising environmental design must first outline a set of generic human needs which should then be matched with appropriate environmental design interventions (Lawton, 2001a). Once these have been established, he argued that the specific needs of an individual can be addressed. Lawton (2001a) maintained that the environment had a very significant impact on individual well-being. Investigating the individual and the environment and the relationship between both was in his view critical to an improved understanding of health and well-being. Lawton (2001a) considered this relationship between universality and individuality by looking at a number of concepts linking people and the environment. He claimed that "personal needs are seen as differentially capable of being satisfied as a function of the ability of the environment to support those needs" (Lawton, 2001a,). Such views are also well embedded in the publication 'Buildings for Everyone: A Universal Design Approach' by the Centre for Exellence in Universal Design at the National Disability Authority (2013).

Referring to the concept of affordance, first proposed by Gibson (1979), Lawton (2001a) describes how the interaction between a person and his/her environment is influenced by the physical characteristics of an object or the physical environment. Affordance allows a behaviour to take place, if the user discovers the characteristic that facilitates a certain function and acts out the associated behaviour (Lawton, 2001a, p. 7.2). Lawton (2001a) argued that an affordance is not the cause of a behaviour, as the user must discover the physical characteristic and act accordingly. The user must actively engage with the environment and therefore "personal need provides the motivation to search for affordances and that the individual characteristics of the

person determine the content of the behaviour that effectively uses the affordance" (Lawton, 2001a, p. 7.2).

This interaction of the physical environment and the individual characteristics of those who engage with this environment has been examined through the 'Person-Environment fit' model (Kahana, 1974; Lawton, Windley & Byerts, 1982). Intrinsic to the analysis of this interaction is the concept of 'environmental press'. Central to this concept is the idea that the physical environment directly affects an individual's ability to execute various activities. Thus the greater the challenges presented by the environment, the greater the environmental press (Eisdorfer & Lawton, 1973). Marshall (2009) describes this phenomena succinctly by stating that "the more disabled you are, the more significant is the built environment. This is because you are, in a sense, a victim of your own environment since you cannot alter it yourself" (p. 4-5). The Person-Environment fit model proposes that congruence between personal needs and environmental press, positively influences environmental and psychological wellbeing, whilst incongruence may result in problems beyond those created by the environment or personal preferences (Kahana et al., 2003). Kahana et al. (2003) also point out that Person-Environment fit incongruence can have negative physical health and mental health consequences.

This Person-Environment fit model and the concept of environmental press shifts the focus away from the person as the cause of their disability onto the context and how the latter either enables or hinders an individual in terms of their activities and participation. For instance, successful ageing relies on a person's ability to organise his/her social and physical environment so s/he can remain functional in their environment (Lewis, 2003; Schwartz, 1974). This emphasis on activity, and in turn participation, is further understood through the idea of Person-Activity-Environment fit which refers to the congruence of individual skills and abilities of a person, the demands of the activity, and the nature of the physical, social and cultural environment (Neistadt, 2000). Within the Person-Activity-Environment model, the user is presented in a more active capacity than the Person-Environment model as illustrated in Figure 5.
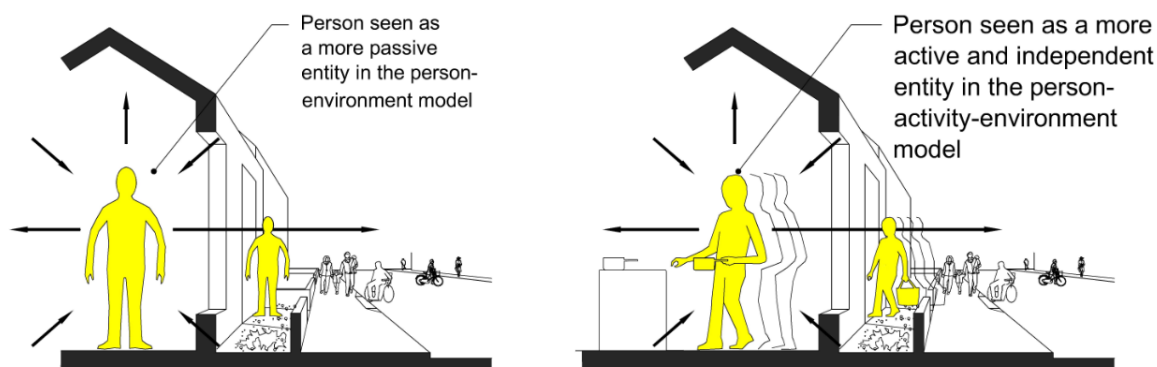
Figure 5 – The Person-Environment model vis-à-vis the Person-Activity-Environment model

2.3. Designing for the whole Person

This Person-Activity-Environment Fit model was advanced in 2001 by the WHO, which published the International Classification of Functioning, Disability and Health (ICF) as a "standard language and framework for the description of health and health related states" (WHO, 2002, p. 2). The ICF argues that a bio-psychosocial model is a useful approach for understanding disability and health; thus a holistic model incorporating both medical and social aspects is recommended. The ICF classification shifts the emphasis from a person's disability to their level of health and functioning in society and acknowledges that all people may experience a health condition at some stage and therefore all people may experience a disability.

The ICF model has greatly influenced medical practice (Smith, 2002) and indeed societal thinking about health and illness (Centre for Excellence in Universal Design at the National Disability Authority, 2013). The ICF attempts to provide a coherent and more comprehensive view of health bringing together biological, individual and social components. It advocates for the integration of biological (i.e. medical condition or disease), with psychosocial (i.e. personal, emotional, community etc.). A person's functioning and disability is conceptualized as a dynamic interaction between health conditions, (disease, disorders, injuries traumas), personal factors (age, social class, gender, personality, attitudes) and environmental factors (attitudes of society, built and physical environment, home availability of carers). In combining biological, individual and psychosocial perspectives, what is most important is that health, disability and functioning are viewed as "outcomes of interactions between health conditions (disease, disorders and injuries) and contextual factors" (WHO, 2002, p.10).

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Health condition

(disorder or disease)

Body Functions
& Structure ←→ Activity ←→ Participation

Environmental
Factors

Personal
Factors

Contextual factors
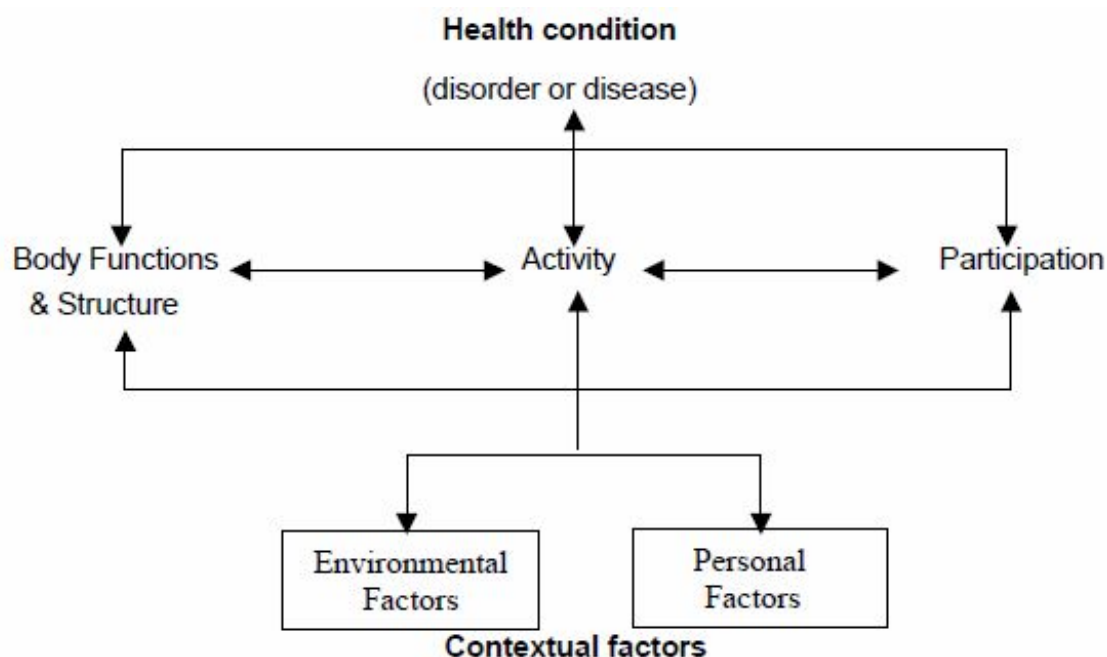
Figure 6 - ICF Model (WHO, 2002)

Figure 6 illustrates that the ICF model (WHO, 2010) recognises the importance of three levels of human functioning including activity and participation. It argues that health is a function of (i) the body or body parts; (ii) the whole person i.e. the activity and (iii) the whole person in the social context i.e. participation. In many ways, therefore, the ICF Model is not that different from what Lawton and other theorists (including proponents of the Person Activity Environment models) were proposing insofar as the ICF model connects the individual to his or her environment and argues that health and well-being cannot be understood exclusively at a "body function" or at an individual level. Disability is identified when there is a dysfunction at one or more of these levels. Where the dysfunction is at the body level, that is, an 'impairment'; at the activity level, this is an 'activity limitation' and where the disability is at the social level, it is 'participation restriction'. Therefore, through this framework "The ICF conceptualises a person's level of functioning as a dynamic interaction between her or his health conditions, environmental factors and personal factors" (WHO, 2010, p. 1).

As mentioned, the bio-psychosocial approach is handled in the ICF by incorporating the biological into the 'body functions and structures' component, spreading the psychological between the 'body functions and structures' and the 'activities' component (the whole person), and spanning the social over both the 'activities' and the 'participation' components. The ICF model places activity at the centre stage and emphasises that it is the negative aspects of the

interaction between a person and his/her environment that limits activity which in turn restricts the individual's participation in society. Most importantly, this activity limitation is a large part of the disability, and not the individual's health condition. The ICF model stresses the importance of social participation and acknowledges the role of the environment in creating disability, thus defining disability as:

> "an umbrella term for impairments, activity limitations and participation restrictions. It denotes the negative aspects of the interaction between an individual (with a health condition) and that individual's contextual factors (environmental and personal factors)." (WHO, 2002 p. 3).

The ICF model along with this definition of disability has much application when considering a condition like dementia where all too often, all of the individual's behaviour is seen through the dementia or 'body/brain functions' level and not through other equally important levels, such as the environment, activity participation and other people including interactions of families and carers with that person. Accordingly, the ICF model provides a useful framework for dementia friendly dwellings from a Universal Design approach as it places human activity (of people living with dementia, their families and carers) and social participation at the centre stage (Centre for Excellence in Universal Design, 2013). The non-medicalisation of dementia, as introduced in Chapter 1, and the 'normalization' of other physical, sensory, cognitive, or intellectual disabilities is dependent upon environments that support human activity and enable social participation.

The ICF model acknowledges the need to enhance the functional capacity and performance of the person by modifying the social and physical environment. It highlights how a person with some form of impairment (body or body part) can be prevented from carrying out activities, thus experiencing 'activity limitation' and how this restriction can lead to social exclusion through 'participation restriction'. Although the ICF model refers to body, it could equally well be applied to brain and to the disability of dementia.

Referring to the ICF model, Froyen (2012) like Marshall (2009) and others, refers to 'deficient people' versus 'deficient buildings' and points to the dominant approach to design which caters

to the ideal of the "symmetrical and athletic Vitruvian body[8]". He points out that this new paradigm moves the focus from the physiological, anatomical, and neurological characteristics of the individual to human activities as the central concern. He embraces the concept of Universal Design and argues that design for everyone should move beyond providing for stigmatized minority groups, but instead should include social and political measures that provide for the whole community in an integrated and inclusive manner. Universal Design is where design "anticipates a diversity of usage scenarios, and continues to support and serve the users in dynamic cycles" (Froyen, 2012, p. 42).

2.4. Conclusion

Based on the literature, this chapter has briefly discussed some of the most relevant theories and models which underpin an understanding of the disability of dementia and the way in which the environment should be designed or customised to minimise this disability for both the individual, their families and carers. In particular the chapter has described the Person-Environment and Person-Activity-Environment models and has attempted to highlight how both are encompassed within the WHO's definition of health, functioning and disability as reflected in the ICF. The literature reviewed and theories discussed have demonstrated that societal thinking around health and disability has changed significantly over the last 50 years, from the perspective that disability is caused by a person's health condition, and the person is seen as a passive victim, to the view that disability is caused or created by society and that much can be done to ameliorate the individual's experience of a health problem. A Universal Design approach to dementia friendly dwellings reflects a commitment to creating enabling environments supporting a range of human abilities. This approach means that the environment does not present as a barrier but rather can be used as a therapeutic tool to facilitate and promote peoples' engagement in activities and their social participation.

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[8] Vitruvian man is a drawing created by the Renaissance artist Michelangelo, based on the works of the architect Vitruvius, which depicts ideal human proportions as represented by a young athletic male figure.

Chapter 3: Universal Design approach for Dementia Friendly Dwellings - Goals and Principles

3.1. Introduction

This chapter examines two main bodies of literature, namely (i) Universal Design and (ii) the design of buildings for people living with dementia. The chapter focuses specifically on design principles and design goals and both concepts are well addressed in these two bodies of literature. At the outset it is important to acknowledge the fact that many different terms and concepts are used by design experts committed to improving the built environment for people in general and for people with a disability.

Based on this literature review we have identified five key concepts pertinent to up-skilling built environmental designers/professionals and other professionals working in the area of designing home dwellings or retrofitting them for people living with dementia, their families and carers. These concepts pertain to (i) design principles, (ii) design goals, (iii) design guidelines, and (iv) best practice. A difficulty identified is that some experts use different terms to describe the same phenomenon. For example, concepts such as principles and features are sometimes used interchangeably as are concepts such as principles and guidelines. For the sake of clarity of presentation, only those concepts as identified by experts writing in the area will be used in this report and will not be changed.

It is also important at the outset to define what some of these terms mean. Based on this literature review, our understanding of terms is as follows:

- design principles are the general statements that needs to be followed in design
- design goals are defined as the purpose of the design challenge
- design guidelines provide specific direction that follow the rules and help to achieve the goals
- design strategies outline potential approaches for implementation and
- best practice provides exemplars or successful examples.

As mentioned, this chapter will report on the literature on Universal Design as well as the literature on the design of dementia friendly buildings using primarily three of these four key concepts: principles, goals and guidelines. This framework is also useful in helping us to better understand the linkages between the two literatures.

3.2. Universal Design – Principles, Goals & Guidelines

Universal Design can be defined as "the design and composition of an environment so that it can be accessed, understood and used to the greatest extent possible by all people, regardless of their age, size, ability or disability" (Centre for Excellence in Universal Design, 2013).

3.2.1 Principles of Universal Design

There is general agreement about some seven key principles of Universal Design (Kose, Preiser & Ostroff, 2001; Preiser & Smith, 2011) as detailed below:

1. Equitable Use – the design is useful and marketable to people with diverse abilities.
2. Flexibility in Use – the design accommodates a wide range of individual preferences and abilities.
3. Simple and Intuitive – the design is easy to understand regardless of the user's knowledge, language skills or current concentration levels.
4. Perceptible Information – the design communicates necessary information effectively to the user, regardless of ambient conditions or the user's sensory abilities.

5. Tolerance for Error - the design minimizes hazards and the adverse consequences of accidental or unintended actions.

6. Low Physical Effort – the design can be used efficiently and comfortably with minimum fatigue.

7. Size and Space for Approach and Use - design provides appropriate size and space for reach and manipulation, regardless of user's body size, posture or mobility.

3.2.2 Universal Design goals

Steinfeld and Maisel (2012) discuss Universal Design as it relates to human performance, health/wellness and social participation and identify design goals as follows:

1. Body fit - accommodating a wide range of body sizes and abilities.
2. Comfort - keeping demands within desirable limits of strength and stamina.
3. Awareness – ensuring that critical information for use is easily perceived.
4. Understanding – making methods of operation and use intuitive, clear and unambiguous.
5. Wellness – supporting health and safety, physically and psychologically.
6. Social integration – treating all groups with dignity and respect.
7. Personalisation – incorporating opportunities for choice and the expression of individual preferences.
8. Cultural appropriateness – respecting and reinforcing positive cultural values and local context

Figure 7 illustrates the links that Steinfeld and Maisel (2012) make between the seven Universal Design principles as discussed earlier and the eight Universal Design goals identified.
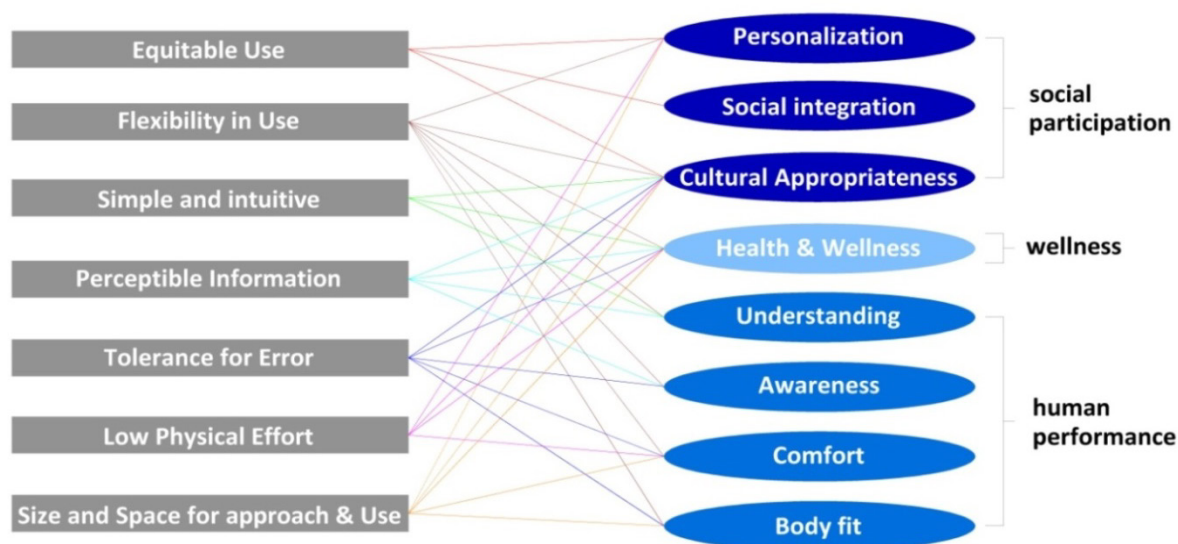
Figure 7 - Relationship between Universal Design Principles and Universal Design Goals (adapted from Steinfeld & Maisel, 2012)

3.2.3   Universal Design guidelines

In addition to identifying these useful Universal Design principles and goals, a number of guidelines associated with each principle have also been identified (Center for Universal Design, 1997). These are now detailed below.

1. Equitable Use
• Provides the same means as far as possible for all users.
• Provide the same means of use for all users: identical whenever possible, equivalent when not.
• Avoid segregating or stigmatizing any users.
• Provisions for privacy, security, and safety should be equally available to all users.
2. Flexibility in Use
• Provide choice in methods of use.
• Accommodate right- or left-handed access and use.
• Facilitate the user's accuracy and precision.
• Provide adaptability to the user's pace.
3. Simple and Intuitive
• Eliminate unnecessary complexity.
• Be consistent with user expectations and intuition.
• Accommodate a wide range of literacy and language skills.
• Arrange information consistent with its importance.
• Provide effective prompting and feedback during and after task completion.

4. Perceptible Information

- Use different modes (pictorial, verbal, tactile) for redundant presentation of essential information.

- Provide adequate contrast between essential information and its surroundings.

- Maximize "legibility" of essential information.

- Differentiate elements in ways that can be described (i.e. make it easy to give instructions or directions).

- Provide compatibility with a variety of techniques or devices used by people with sensory limitations.

5. Tolerance of Error

- Arrange elements to minimize hazards and errors: most used elements, most accessible; hazardous elements eliminated, isolated, or shielded.

- Provide warnings of hazards and errors.

- Provide fail safe features.

- Discourage unconscious action in tasks that require vigilance.

6. Low Physical Effort

- Allow user to maintain a neutral body position.

- Use reasonable operating forces.

- Minimize repetitive actions.

- Minimize sustained physical effort.

7. Size and Space for Approach and Use

- Provide a clear line of sight to important elements for any seated or standing user.

- Make reach to all components comfortable for any seated or standing user.

- Accommodate variations in hand and grip size.

- Provide adequate space for the use of assistive devices or personal assistance.

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The Universal Design principles, goals and guidelines are important for guiding the design of general housing. With respect to the design of the home environment, Universal Design principles and guidelines have mostly been applied in connection with physical and sensory impairments. However, they are increasingly being taken into account regarding the needs of people with cognitive difficulties. The next section will examine the understanding of design goals and principles in the literature on the design of buildings for people living with dementia, their families and carers.

3.2.4 Universal Design Guidelines for Homes in Ireland

As discussed in section 1.9, the Centre for Excellence in Universal Design at the National Disability Authority has produced draft guidelines titled 'Universal Design Guidelines for Homes in Ireland' (2014) in relation to the design of new dwellings. These Universal Design Guidelines build on the seven principles of Universal Design but in particular use the following four principles;

1. Integrated into the neighbourhood.
2. Easy to approach, enter and move about.
3. Easy to understand, use and manage.
4. Flexible, cost effective, safe and adaptable over time.

The first principle 'Integrated into the neighbourhood' has been introduced to ensure that the dwelling is located in close proximity to local services and public transport and is well integrated into the community. While location is not specifically referred to in the Universal Design principles, the principle of 'Equitable Use' should inform the location of a dwelling to ensure it complies with the guidelines associated with this principle. The latter include the following: (i) provides the same means as far as possible for all users and the same means of use for all users, (ii) is identical whenever possible or equivalent when not, (ii) avoids segregating or stigmatizing any users, and (iii) provides for privacy, security, and safety – the latter should be available on an equitable basis to all users.

The next two Universal Design principles "Easy to approach, enter and move about in" and "Easy to understand, use and manage" encapsulate all seven Universal Design principles using plain easily understood language.

The final Universal Design principle of 'Flexible, cost effective and adaptable over time' refers specifically to the Universal Design principle of 'Flexibility in Use'. However this Universal Design principle also ensures that a dwelling is economically sustainable and can be adapted in line with the resident's needs so that it becomes a lifetime home that responds to the entire lifecycle.

The previous sections outlined main aspects of the Universal Design approach as encompassed by the Steinfeld and Maisel Universal Design goals (Steinfeld & Maisel, 2012), the internationally recognised Universal Design principles, and the four principles adopted in the 'Universal Design Guidelines for Homes in Ireland' (Centre for Excellence in Universal Design, 2014). The section to follow will now report findings from some key international literature on the topic of the design of dementia friendly buildings. This has been done to provide a basis for examining the congruence between dementia friendly design and Universal Design. The objective is to draw out the design issues that are dementia specific and not covered specifically by Universal Design, issues that will need to be included in the final 'Universal Design Guidelines for Dementia Friendly Dwellings'.

3.3. Design of Buildings for People Living with Dementia – Design Goals and Design Issues

It could be argued that the literature on the design of buildings for people living with dementia has been strongly influenced by architectural design literature and more recently by that on Universal Design. Many dementia experts writing on the topic of design of buildings for people living with dementia have drawn extensively on concepts introduced by design experts. For example, Cohen and Weisman (1991) have referred to the importance of therapeutic goals in designing supportive living for people with dementia. Calkins (e.g. 2001), an architect, explicitly compares design of buildings for people living with dementia and Universal Design and shows that their respective approaches align well with Steinfeld and Maisel's (2012) approach. Building on the Universal Design literature the section to follow will discuss some of the key design goals and design issues for dementia reported in the literature. An argument marshalled is that there is an absence of research undertaken on the topic of the design of dwellings for people living with dementia, their families and carers. Where possible, efforts will be made to link the two bodies of literature and, based on our review of the literature, a set of goals and design issues appropriate to the design or adaptation of dwellings for people living with dementia, their families and carers will be articulated.

3.3.1.   Existing design or therapeutic goals and principles

In Chapter 2, the reader was introduced to the contribution the late Powel Lawton made to the areas of ageing, dementia and the built environment (see pages 29-30). Although Universal Design experts have much to contribute to and have strongly influenced the design of buildings

for people living with dementia, it was Lawton who as early as the mid-1960s was arguing that the person and the environment comprise an inseparable unit, with all parts participating and affecting the individual's identity. In the early 1970s he was hypothesizing about the importance of privacy to wellbeing in long-term care and later in 1973 advanced his docility hypothesis arguing that ironically, as functioning declines, environmental support becomes all the more important, otherwise the person with reduced competencies will become passive (Eisdorfer & Lawton, 1973; Lawton, 1977).

A key element of Lawton's thesis was his strong belief that all too often older people, including those with dementia, adapt their behaviour to their environments rather than conversely the environment being adapted to suit their behaviours. In fact, it was his research into how environmental factors affect people living with dementia which led in the mid-1970s to the development of the first ever US specialist nursing home specifically for older people with Alzheimer's disease. Undoubtedly, his work continues to influence the design of facilities for people living with dementia.

Interestingly, in their discussions about the post-occupancy evaluation of this first specific care home (at the Weiss Institute in Philadelphia), Lawton, Fulcomer and Kleban (1984) described some general design goals for buildings for people living with dementia. These included the creation of treatment environments in which "structure and behavioural systems could help compensate for the massive physical, cognitive, psychological, and social deficits exhibited by these older patients" (Lawton, Fulcomer & Kleban, 1984, p. 736). Specific goals included enhancing sensory functioning, increasing autonomy in performing activities of daily living, enhancing cognitive functions specifically memory orientation, increasing the meaningful use of time, increasing social interactive behaviour and enhancing the sense of self.

Later, in the context of Alzheimer's disease, Lawton (2001b) identified four types of user needs. These were the need to: (i) decrease challenging behaviours such as pacing, aggression, (ii) increase social behaviour arriving at a balance between excess stimulation and isolation, (iii) increase activity through physical and sensory stimulation, and (iv), increase positive and decrease negative feelings.

Lawton (2001b) advanced his theory further by outlining the following needs which he defined as 'quality of life user need domains':

- **Autonomy**: Residents take initiative and make choices for their lives and care.

- **Individuality**: Residents express their preferences and pursue their past and current interests (while living at the nursing home), maintaining a sense of their own personal identity and continuity with their past.

- **Dignity**: Residents perceive that their dignity is intact and respected and do not experience feelings of being belittled, devalued, or humiliated.

- **Privacy**: Residents experience a sense of bodily privacy, have the ability to keep personal information confidential, and have sufficient opportunities to be alone and to communicate and interact with others in private

- **Enjoyment**: Residents express or exhibit pleasure and enjoyment, verbally and non-verbally. Conversely, they do not express or exhibit unhappiness, distress, or lack of enjoyment.

- **Meaningful activity**: Residents engage in discretionary behaviour, either active activity or passive observation, that they find interesting, stimulating, and worthwhile. Conversely, they tend not to be bored with their lives.

- **Relationships** (interactions): Residents engage in meaningful person-to-person interchange where the purpose is social.

- **Comfort**: Residents experience minimal physical discomfort, including symptoms such as pain, aches, nausea, dizziness, constipation, and itching, nor discomfort from being cold, hot, thirsty, or in an uncomfortable position. They perceive that staff notice and attend to their physical comfort.

- **Spiritual well-being**: Residents perceive that their needs and concerns for religion, prayer, meditation, moral values, and meaning in life are met.

- **Functional competence**: Residents function independently (in the nursing home) in keeping with their abilities and preferences.

It is very evident in reviewing the contributions made by later dementia experts writing on the topic of designing buildings for people living with dementia (Calkins & Sloane, 2013; Day, Carreon & Stump, 2001; Fleming & Purandare, 2010; Sloane et al., 2005) that the works of both Lawton (2001a, 2001b) and the Universal Design experts influenced their thinking. As mentioned, most of these experts writing about the design of buildings for people living with dementia concentrate on the design of residential care settings rather than domestic dwellings and the review for this research has consistently revealed the paucity of literature dedicated to the design of dwellings for people living with dementia (O'Malley & Croucher, 2005). Having

reviewed the general literature on the design of buildings for people living with dementia, however, we are of the firm belief that such valuable writings can be built on. We can contribute to this literature by adapting and revising the design principles already developed to underpin the design of buildings for this group of people and use them to inform the Universal Design approach for dementia friendly dwellings.

The section to follow reports on some of the contribution of several dementia experts, especially Marshall (e.g. 2009) and Calkins (e.g. 2001) since both, in our view, have most relevance to the development of design principles that will underpin the Universal Design approach for dementia friendly dwellings[9].

3.3.2.   Existing goals and design issues for dementia friendly dwellings - a basis for a Universal Design approach for Dementia Friendly Dwellings

Several institutes and individual researchers have formulated building design principles and building design goals to improve quality of life for people living with dementia. Our review of this literature reflects substantial overlap and similarity between these various experts writing on the topic. It also shows a consensus about the design issues that should be taken into account when designing buildings for people living with dementia, their families and carers. This international consensus on principles of design for buildings for people living with dementia has been summarised by Marshall (2001) and will be reviewed in the section to follow.

Marshall's contribution

The international consensus on design, as highlighted by Marshall's in Judd, Phippen and Marshall (1998), stipulates that design should: (i) compensate for the disability of dementia; (ii) maximise independence; (iii) enhance self-esteem and confidence; (iv) be orientating and understandable; (v) reinforce personal identity; (vi) welcome relatives and the local community; and (vii) allow control of stimuli (Marshall, 1998). Although the terminology used here is different (Marshall writes about principles and Universal Design experts refer to these as design goals), it is evident in analysing Marshall's (1998) principles that several of the already mentioned Universal Design goals (see page 39) are contained within these principles. Such

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[9] Whilst both these authors writings have much relevance it must be remembered that their respective works concentrate largely on long stay residential care facilities and not on community dwellings.

overlaps include design to promote awareness, to support health and well-being, and to encourage social integration.

Marshall (1998, p. 11) argues that if "buildings and their carers relate to people living with dementia as individuals, reinforce their sense of well-being and provide opportunities for them to practise their remaining skills, then people living with dementia are helped to function at their greatest potential". She classifies this design guidance into 'principles' and then outlines more specific 'features' of dementia friendly environments which contribute to best practice (Marshall, 1998).

Marshall (1998) summarises a consensus on the design features that need to be incorporated when designing long-stay residential care facilities and in order to provide quality care. These include the fact that the layout should be small in size and domestic. There should be ample scope for ordinary activities (unit kitchens, washing lines, garden sheds). Different rooms should be provided for different functions equipped with furniture and fittings that are age appropriate. There should be a safe outside area. The facility should have single rooms sufficiently big to accommodate a reasonable amount of personal belongings. Good way-finding interventions such as signage should be used with multiple cues where possible such as sight, smell and sound. Objects rather than colour should be used for orientation and visual access enhanced. There should be control of stimuli especially noise.

Calkins' contribution

In keeping with Marshall's (1998) recommendations, Calkins (2001) and her colleagues writing from the US (e.g. Calkins & Sloane, 2013) and drawing on the international literature outline a set of accepted design goals and principles for the design of buildings for people living with dementia. They note that early work in this area often focused on deficits such as wandering, agitation or disorientation (in line with Lawton's earlier writings). They point to the fact that the more recent research (Calkins, 1988; Cohen & Weisman, 1991; Lawton, 1983) tends to place an emphasis on therapeutic goals (in line with Lawton's quality of life domains). Calkins' and her colleagues' typology probably follows more specifically the terminology and approach used by Universal Design experts in so far as Calkins identified therapeutic goals which she shows are supported by principles for design of buildings for people living with dementia,

where each design principle has a number of associated design guidelines (Calkins, 1988; Calkins, 2001; Calkins & Sloane 2013).

Similarities between Marshall's and Calkin's Perspectives on Design for People Living with Dementia

There is substantial agreement, between Marshall (e.g. 1998) and Calkins (e.g. 2001), regarding their fundamental thinking on designing buildings for people living with dementia (see Figure 8), although interestingly one writes from a social science perspective and the other is an architect. The colour coded cross-walk links elements from both writers. Some differences emerge insofar as Marshall (1998; 2009) states that the design of buildings for people living with dementia should enhance self-esteem and confidence, demonstrate care for staff, and allow control for stimuli, whilst Calkins (1987; 2001) calls for such design to reflect safety security, and privacy.
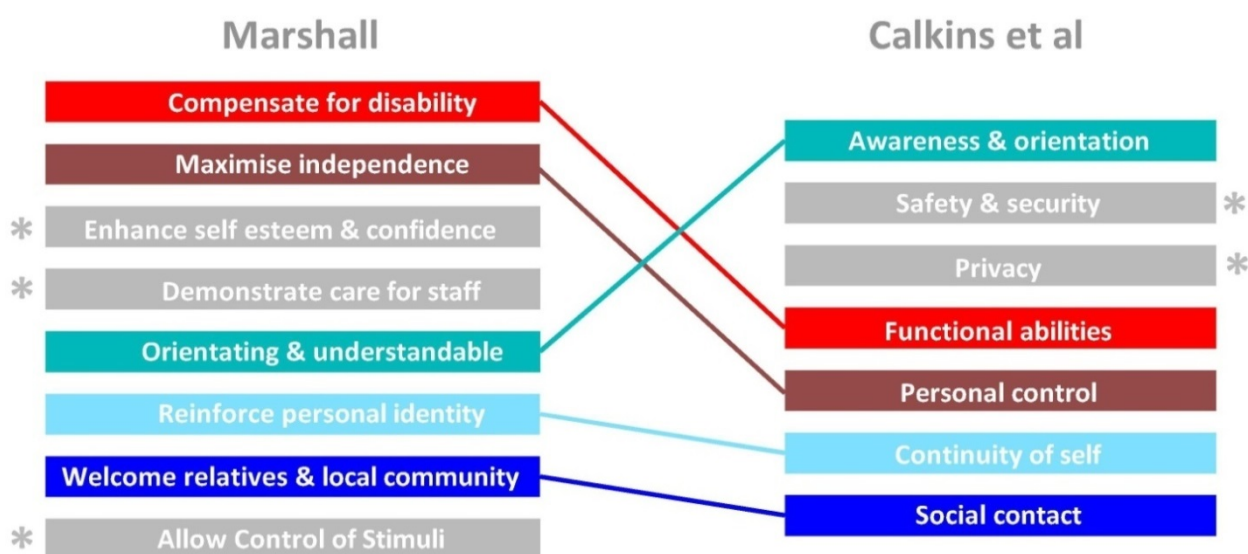
Figure 8 - Comparison of Marshall's Design Principles and Calkin's Design Goals

Calkins et al. (2013; 2001; 1988) specify a range of design principles, along with specific guidelines associated with each principle, which help achieve the goals set out earlier. Therefore, while they provide only five principles, the latter are expanded upon in much greater detail through the sixteen associated guidelines. The features of good design of buildings for people living with dementia, as articulated by Marshall (1998) and the principles as identified by Calkins (2001; Calkins & Sloane, 2013), are set out in Figure 9.
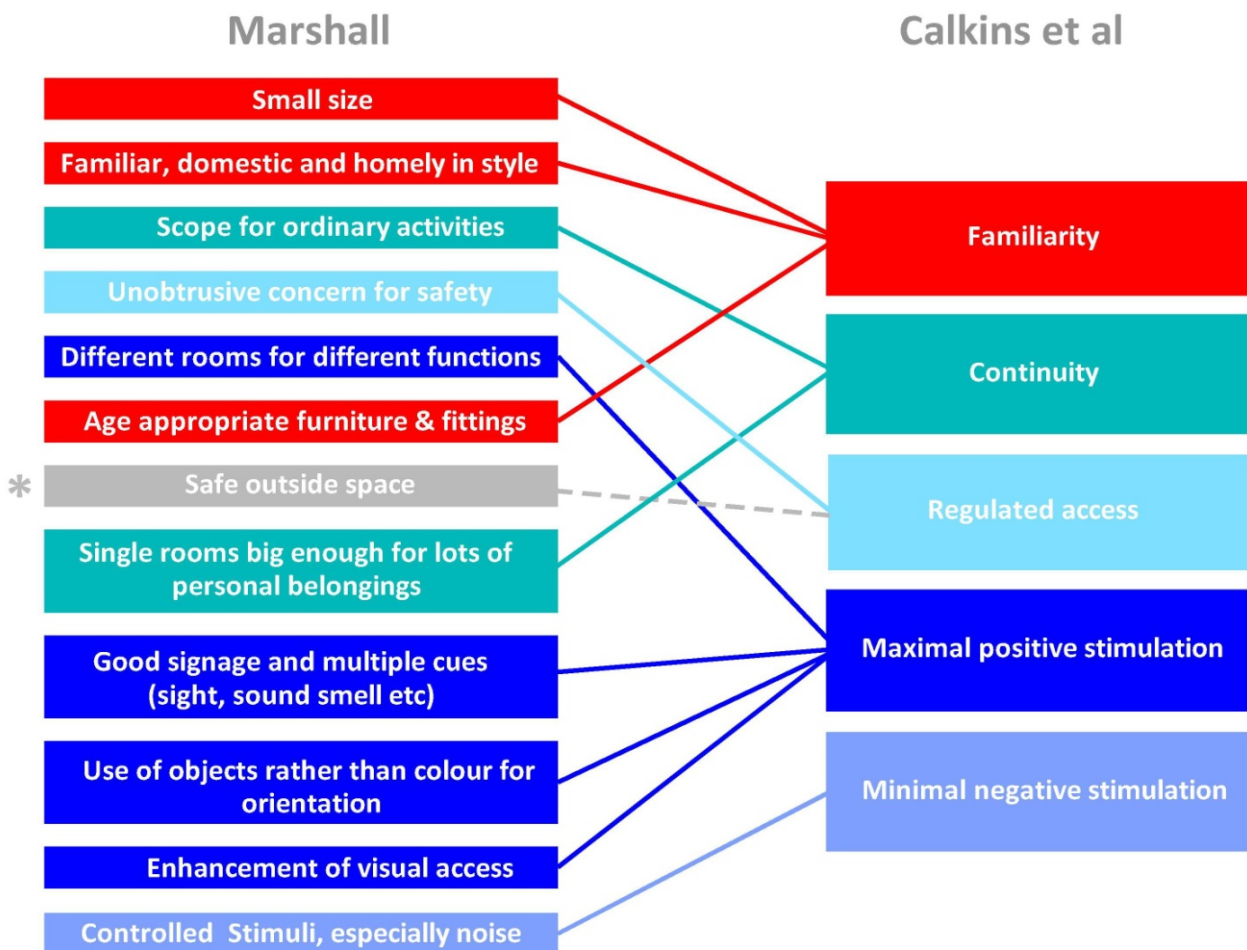
Figure 9 - Comparison of Marshall's design features and Calkin's Design principles

Figure 9 shows that Marshall's (1998) design features fit into the broader design principles as set out by Calkins (2001; 1987) and her colleagues (Day & Calkins, 2002; Calkins & Sloane, 2013). While Marshall (1998) identifies a number of features that help create a more familiar environment (familiar, domestic and homely in style), Calkins et al. (e.g. 2013) emphasise 'Familiarity' as a stand-alone principle. On the other hand, Calkins' typology does not refer to the importance of outside space - a feature of good design of buildings for people living with dementia identified elsewhere in literature. Outside space is important for a wide variety of reasons including sensory stimulation, physical exercise, contact with nature or the execution of normal activities of daily living (Girardet & Schumacher, 1999; Pollock, 2001; Pollock & Marshall, 2012; Timlin & Rysenbry, 2010). Thus drawing on the works of both of these experts brings richness to the topic and we would argue that familiarity and safe and secure outside

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spaces should be included in any list of dementia friendly design goals from a Universal Design approach.

A shortcoming of Marshall's (e.g. 1998) and Calkin's (e.g. 2001) design principles, from the perspective of this research review, is that the design goals and features developed were for residential long-stay care settings and not for home dwellings.

3.3.3. Goals for the Design of Dementia Friendly Dwellings – Applying a Universal Design approach

While the design principles, goals and features, as outlined in the previous section of this chapter, were intended to underpin the design of long-stay residential care settings for people living with dementia, most can also be easily applied to designing dwellings for the same client group (van Hoof et al., 2010a; 2010b). We would argue that there are probably two exceptions. First, for home dwellings, reference to including the needs of care staff (formal caregivers in residential care settings) should be replaced by a reference to the need to recognise the importance of family members and caregivers (both co-resident and non-resident) and where appropriate formal carers and health care professionals visiting the home. Secondly the statement 'design should welcome relatives and the local community' might be better formulated as 'design should support connection and engagement with relatives and the local community'. In this context, it is also important to think about the dwelling in relation to the neighbourhood or community in which it is situated. It is also important to consider the dwelling in terms of optimum location (where there is a choice of location), interaction with adjacent public spaces, and the design or approaches and entrances to assist with orientation for those leaving or returning to the home. Optimum location in terms of convenience for formal carers and health care professionals visiting the home is also important.

Providing a safe and secure environment is a priority goal in designing buildings for people living with dementia but given that where an overemphasis is placed on safety over autonomy, environments have been found to have a negative impact on the well-being of people living with dementia, it is our view that 'design should promote autonomy and choice' and this should be included in a set of design goals for dementia friendly dwellings from a Universal Design approach. Finally, given the increasing importance of ambient assistive living (AAL), it would be

prudent to include a principle that design should promote the ethical use of AAL and/or promote the use of enabling assistive technology.

Building on Marshall's (e.g. 1998) and Calkin's (e.g. 2001) contribution we have therefore set out the main goals for universally designing dementia friendly dwellings for people living at home with dementia and their families and carers. The following sections look at each of the dementia friendly dwelling design goals to see how they align with the Universal Design goals identified by Steinfeld and Maisel (2012). Consideration is also given to whether any additional Universal Design goals are needed to ensure that the design goals are appropriate for dwelling design.

1. Design should recognise the importance of family members and caregivers, (both co-resident and non-resident) and care staff visiting the home.

Universal Design is about providing an enabling environment for all people, irrespective of age, size, ability or disability. Since Universal Design covers all people, it automatically includes family members and caregivers who are living in or visiting the home of a person living with dementia. However, people living with dementia are likely to require some level of care if they are to continue to live in their own home for as long as possible. Family members and sometimes formal carers play a critical role in caring for people with dementia in their own homes. Therefore it is vital that families, friends and neighbours as well as formal carers and health care professionals are supported by the physical home environment to provide and sustain the proper level of care for people living with dementia. This is implicit in the Universal Design principle of making 'family homes suitable for all people, regardless of age, size, ability or disability' (Centre for Excellence in Universal Design, 2014, p. 1), but because of the significant role that families and others play in caring for people living with dementia at home and the importance of the physical environment in supporting that role, we believe that it needs to be stated explicitly as a goal for designing dementia friendly dwellings from a Universal Design approach.

2. Design should support connections and engagement with relatives and the local community.

People living at home with dementia and their families and carers want to and indeed enjoy going out and taking part in social activities outside the home, all of which have been found to contribute to a well-being and a better quality of life. Giving careful consideration to where new dwellings will be located can be an important way of supporting people living with dementia and their family members and caregivers to remain connected with the local community. This goal is therefore in keeping with the Universal Design goals of 'Wellness' and 'Social Integration' (see page 38).

3. Design should compensate for disability.

This design goal acknowledges that dementia is a disability and that it can often be accompanied by other age related illnesses or disabilities. The goal extends to other family members living with the person with dementia who may be older themselves (spouse or sibling) and who may have a disability. The Universal Design goal 'Body fit' refers to the need to accommodate a wide range of body sizes and abilities. This goal can also refer to Universal Design Goal 2 which takes into account body abilities (see page 38).

4. Design should reinforce familiarity.

This design goal acknowledges that the creation of a familiar environment is important for people living with dementia whose long term memory may still be intact. Design features from an earlier part of their life may be more recognisable. The concept of familiarity will be discussed elsewhere in this report and is also included as a key design issue in section 3.3.4.

5. Design should maximise independence.

Independence can be defined as the ability to complete basic daily tasks. These tasks are usually divided into three; basic activities of daily living, instrumental activities of daily living and leisure activities. Dementia results in a progressive decline in cognitive performance. This is important to know, as a person's ability to complete basic daily tasks is adversely affected by impaired cognition. People living with dementia often have difficulty completing basic daily tasks and often require the assistance of informal and formal carers. Universal Design can help a

person living with dementia to maintain independence and help carers in supporting the person to maintain independence as the condition progresses. If the home environment and products in it are designed to be intuitively usable by people living with dementia, it follows that their ability to complete activities of daily living will improve, which in turn can lead to maintaining independence and heightened self-esteem. For example, one of the aims of the proposed guidelines is to help people living with dementia and their families to remain living at home for as long as possible and desirable, both in terms of their own abilities and the ability of relatives, friends and formal carers to support them to do so. Recent UK research shows that older people in general and people with dementia wish to live in their own homes for as long as possible (Tinker, 2014). Adapting the environment to meet the needs of people living with dementia and their families is an important step towards maximising human function and following on from that independence. Given that Universal Design goals incorporate support for human performance and health/wellbeing the goals for the design of dementia friendly dwellings regarding maximising independence seem to align with these Universal Design intentions.

Maximising independence should also apply to the design process to ensure that, wherever possible and appropriate, those living with a person who has dementia can direct the design to ensure it meets their needs. In accordance with this, the Universal Design goal relating to 'Personalisation' addresses issues around choice and expression of individual preferences.

6. Design should support meaningful activity.

Remaining engaged in activities of daily living is therapeutic, reinforces personal autonomy and identity, and may help to reduce further decline in activities of daily living. In terms of designing for people living with dementia, supporting meaningful activity helps maintain existing patterns of activity which may be personal and cultural. Therefore this goal reinforces certain Universal Design goals such as 'Wellness', 'Personalisation' and 'Cultural appropriateness' and is thus in line with a Universal Design approach.

7. Design should be easy to orientate and to understand.

The main symptoms of dementia are memory and cognitive loss including the loss of certain spatial processing abilities which can lead to disorientation and anxiety. To compound these

issues, people diagnosed with dementia may also experience sight or hearing difficulties or other age-related difficulties. This goal seeks to ensure that the environment provides as much orientation as possible and is easily understood and accords with the Universal Design goals relating to 'Awareness' and 'Understanding'.

8. Design should allow control of stimuli.

Negative environmental stimuli such as excessive noise can cause annoyance (Institute for Public Health in Ireland, 2006) and can be distressing for people living with dementia. Conversely, positive environmental stimuli such as light, fresh air and sunshine can be therapeutic. Noise, for example, can have a negative impact on many people through disturbing sleep. Noise can even adversely affect a person's physiology as, for example, raising blood pressure (Bluyssen, 2009). Therefore, the control of stimuli is important in terms of wellbeing and conforms to the Universal Design goal aimed at supporting wellness.

9. Design should promote autonomy and choice.

While autonomy and choice can be considered as basic human rights, their promotion in terms of people living with dementia has another dimension. Consider, for example, a person living with dementia who always enjoyed playing the piano and who is now attending a day centre where she is strongly encouraged to participate in Bingo and denied the opportunity to participate in on-going music sessions also taking place there. Nobody there knows that she loves music. This person's sense of autonomy is denied. Choice and autonomy can help people living with dementia to remain engaged and can stimulate activity, both of which have a therapeutic affect and may help maintain activities of daily living.

As stated earlier this goal must also refer to the design process to ensure that people living with dementia play a meaningful role when it comes to design decisions that will ultimately dictate the characteristics of their dwellings. The Universal Design goals around Social Integration and Personalisation (which references choice and expression of individual preferences) are aligned with autonomy and choice, both in terms of the built environment and the Universal Design process.

10.Design should enhance self-esteem and confidence.

Memory impairment, disorientation in time and place and a decline in cognitive ability can have a negative impact on an individual's self-esteem and confidence. A more supportive dwelling can assist people living with dementia to carry out their activities of daily living by simplifying tasks and by providing cues for certain activities. While continued engagement in meaningful activities can help with self-esteem and confidence, it also supports the Universal Design goals of 'Wellness' and 'Social Participation'. In addition, involving people living with dementia directly in the design process and, where possible, giving them a voice may also enhance self-esteem and confidence.

11. Design should reinforce personal identity.

Reinforcing personal identity or the continuity of self is regarded as an important goal in designing dwellings for people living with dementia. While the concept of reinforcing personal identity or personalisation has particular relevance for designing dwellings for people living with dementia, it is an important part of dwelling design in general. Cooper Marcus and Sarkissian (1986) argue that housing design should provide the opportunity for personalisation of dwellings through territorial expression, personal additions, and personalisation of entrances. 'Personalisation' has been selected as a specific Universal Design goal where choice and expression of personal preferences is encouraged. Referring again to the design process, ideally, if the occupant participates in the design of the dwelling the personalisation process is built in from the very start.

12. Design should promote the use of technology in an ethical way.

With the ever increasing role of AAL in dementia care it is important that any technology is used in an ethical manner to ensure the rights and preferences of people living with dementia are respected. Technology should never be used as a substitute for human care but rather should wherever possible complement personal care services. Again the Universal Design goal of 'Social Participation' urges respect and dignity for all groups.

13. The need to include 'Wellness' as a goal?

While it could be argued that all of the design goals discussed so far are aimed at supporting wellness, in line with Steinfeld and Maisel's (2012) Universal Design goals, it may be possible to include the promotion of wellness as a design goal. Given that this is in many ways an overarching goal, it may also make sense to place it as the first design goal. This goal is therefore included as follows;

Design should support wellness and contribute to health promotion, avoidance of disease, and prevention of injury for the person living with dementia, their families and carers

14. The need to include 'Cultural Appropriateness' as a goal?

Finally, the issue of cultural appropriateness is essential to all design and even more important for dwelling design. Dwellings must be contextually sensitive, but also acceptable for the occupant in terms of layout and design. Familiarity is an important aspect of dementia friendly dwellings from a Universal Design approach and it is suggested that the residential environments of people living with dementia should reflect what is familiar and identifiable to them. In an increasingly diverse and multi-cultural society, creating familiar or appropriate environments has become a more complex challenge. Judd (1998) argues that "the idea of home must, by definition, be culturally appropriate" (p. 16) and that some features considered typical or familiar in one culture, may be unusual and disorientating in another. In proposing cultural sensitivity as a Universal Design Goal, Steinfeld and Maisel (2012) propose "Culturally appropriateness - Respecting and reinforcing cultural values and the social and environmental context of any design project" (p. 90). Incorporating a version of this goal into this current research creates the following;

Design should be culturally appropriate and respect the local social and environmental context.

To reiterate the aforementioned goals, include the new additions, and reorder them, placing the design goal relating to 'Wellness' first, the final Universal Design approach for Dementia Friendly Dwellings - Design Goals, are as follows;

1. Design should support wellness and contribute to health promotion, avoidance of disease, and prevention of injury for people living with dementia, their families and carers

2. Design should recognise the importance of family members and caregivers, (both co-resident and non-resident) and formal carers and health care professionals visiting the home

3. Design should support connections and engagement with relatives and the local community

4. Design should compensate for disability

5. Design should reinforce familiarity

6. Design should maximise independent living

7. Design should support meaningful activity

8. Design should be easy to orientate and to understand

9. Design should allow control of stimuli

10. Design should promote autonomy and choice

11. Design should enhance self-esteem and confidence

12. Design should reinforce personal identity

13. Design should promote the use of technology in an ethical way

14. Design should be culturally appropriate and respect the local, social and environmental context.

3.3.4. Design issues in relation to dementia friendly dwellings – Applying a Universal Design approach

As discussed earlier, the design issues raised by Marshall (e.g. 2009) and Calkins (e.g. 2001) refer specifically to residential long-stay care settings and not home-dwellings. Therefore, in a similar manner to that adopted in Section 3.3.3., the next section will look at design issues highlighted by Marshall and Calkins to determine firstly, if they need to be amended/adapted in line with the private residential context, and secondly how they inform or are congruent with the Universal Design approach.

Marshall's 'design features' provide a good basis on which to identify a set of dementia friendly dwelling design issues (Marshall, 2009; 1998). In the context of private dwellings, some features such as 'small size' do not need to be included. Others such as 'Familiar, domestic and homely in style' or 'Age appropriate furniture and fittings' may be reformulated and amalgamated to

refer to the concept of familiarity which has emerged as a very important design issue for people living with dementia and their families.

In addition, a number of other design issues specific to domestic dwellings, such as encouraging a participatory design approach, or proximity and integration into the local community, will need to be included. In response to this, we propose that the design issues outlined below need to be considered with respect to a Universal Design Approach for Dementia Friendly Dwellings. These include the issues identified by Marshall (1998) and Calkins (2001), but also include design issues specific to private dwellings.

The next sections look at these dementia friendly design issues in detail to examine the convergences, divergences and tensions which may exist between each along with the seven Universal Design principles (see section 3.2.3.) and the four principles in Universal Design Guidelines for Homes in Ireland (Centre for Excellence in Universal Design, 2014). Where dementia friendly design issues are already covered by the Universal Design principles or by the four principles in Universal Design Guidelines for Homes in Ireland, then this overlap is highlighted and it is identified that these issues are already catered for in the Universal Design approach and thus do not need to be addressed separately. On the other hand if the dementia specific issues are not covered by the Universal Design approach then this will be highlighted to ensure that these are included in the guidelines. This refers not only to physical design features, but also to the design process to ensure maximum inclusion and to ensure that the voice, needs and preferences of people living with dementia are heard. As a result of the analysis applied in the following sections, some of the design issues will be amended or amalgamated in order to simplify these issues and make them more user-friendly.

1. Encourage a participatory design approach where people living with dementia, carers and other family members can take part in the design process.

At the beginning of this section we discussed the issue of Universal Design as a process and the need for stakeholder engagement and design participation. This issue was also raised by various stakeholders who argued for a more inclusive process where the voices of people living with dementia would be heard and their needs and preferences understood. Many of the principles included here such as the 'Use of familiar design', 'Promoting meaningful activities and

'Personalisation' would all benefit from occupant or carer participation in the design process, where possible. Figure 10 illustrates the Universal Design process which moves through a number of stages including 'Discover', 'Define', 'Develop', and 'Deliver'.
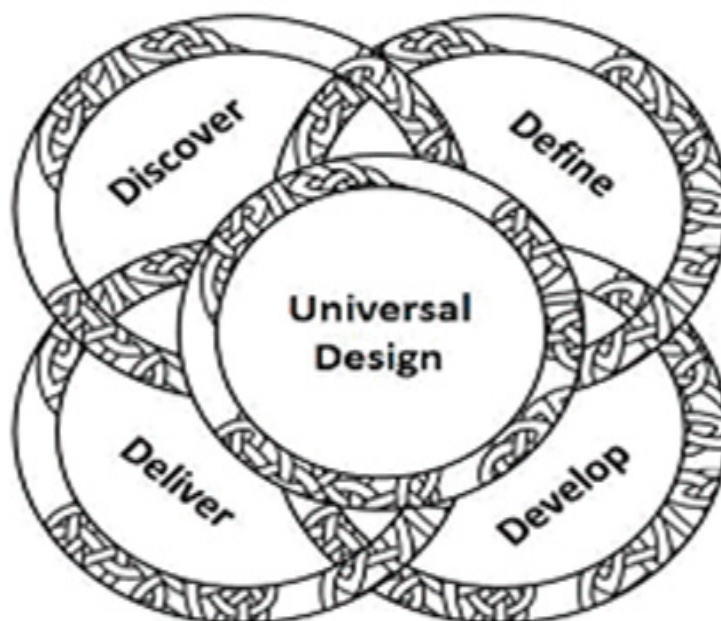
Figure10: The Universal Design Process (Centre for Excellence in Universal Design, 2013)

In terms of adapting existing dwellings, it was pointed out by stakeholders that this can cause confusion and anxiety for a person living with dementia who may not recognise the dwelling as his/her own if the changes are significant. The view that a person should remain at home, if possible, during the period of time that home adaptations are being carried out in order to experience the changes more gradually is one option. Where the works are extensive and make it impossible to remain living during work in progress, the question arises as to whether the person should be brought back periodically to see the work as it progresses? In either case the works will involve some level of construction, noise and disturbance, which could potentially distress a person living with dementia irrespective of whether he/she remains at home or merely visits the dwelling during the construction phase. These issues are part of the design process and onsite implementation phases and need to be considered as an integral part of any principles which constitute the Universal Design approach for Dementia Friendly Dwellings guidelines.

This issue is deemed important enough to retain as originally stated and it will become part of the design guidelines.

2. Promote proximity to, and integration with community or neighbourhood.

The principle of proximity and integration with the community provides opportunities for greater interaction between the person living with dementia and local residents including family members and friends. It facilitates a person to go out into the neighbourhood without the need for a car, or even public transport, thus enabling greater informal social interaction and participation in everyday activities. This principle supports a number of dementia friendly design issues such as 'independence', meaningful activities, autonomy and choice, self-esteem and confidence, and connections and engagements with relatives and local community. While the current Universal Design principles do not include any references to location or integration with the community, the principle of 'Equitable use' would suggest that the location of dwellings for people with dementia should not be treated any differently than other user groups. In the draft guidelines for Universal Design Homes for Ireland (Centre for Excellence in Universal Design, 2014) the first design principle calls for Universally Designed homes to be 'Integrated into the neighbourhood' (p. 8).

The guidance states that development sites for new homes should be "well connected locally with easy access to transport links and places to socialise and shop" (Centre for Excellence in Universal Design, 2014, p. 23).

3. Use familiar design with the use of recognisable features that are consistent with users expectations.

This has been included to account for the fact that many people living with dementia experience short-term memory loss whilst their long-term memory (earlier semantic and episodic memory) still remains intact. It has been argued therefore that design features familiar to a person from his/her earlier life will be more easily understood and usable if memory becomes impaired. This principle of familiarity, which is one of the most important principles in designing dwellings for people living with dementia and their families, is often implemented in long-stay residential care through the creation of a domestic or homely environment.

As this research focuses on domestic dwellings, then the creation of a domestic setting is a natural and automatic outcome. However, familiarity is often interpreted quite literally as the

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use of an interior design style or objects that represent earlier eras. Calkins (2001) argues that the Universal Design principle 'Simple and intuitive' promotes design that meets users' expectations and thus in some ways supports the principle of familiarity. She however cautions about the 'Simple and Intuitive' principle and some other Universal Design principles such as 'Equitable use', 'Flexibility in use' and 'Low physical effort' as the latter may promote novel design solutions intended to facilitate easier use for a wide range of people (Calkins, 2001). However, a new design may rely on some level of rationalization on behalf of the first time user, which may be problematic for a person living with dementia whose ability to learn how to use a new object may be compromised. Maki and Topo (2009) examine Universal Design principles in the context of design for people living with dementia and they propose that the 'Simple and Intuitive' principle eliminates unnecessary complexity where use is easily understood regardless of the user's knowledge, experience, language skill or current concentration levels. This also supports users with dementia and they state that;

> "For those with memory problems or dementia it implies that the use of the product needs minimal or no learning and that it reminds about previous products or previous experiences enough to avoid confusion and stress, and to help in using long term memory." (Maki & Topo, 2009, p. 64)

Maki and Topo (2009) make an interesting point in relation to design that reminds a user about previous products or previous experiences. The subtle but important distinction between the literal meaning of familiarity, where something design-wise must be immediately familiar, and the more subtle meaning where something 'reminds' a person of a previous experience is made. The concept of 'affordance', which was discussed earlier in this report as that which allows a certain behaviour to take place if the user discovers the characteristic of the object that facilitates a certain function, is important here. Norman (2002) describes the theory of affordance as the "perceived and actual properties of the thing, primarily those fundamental properties that determine just how the thing could possibly be used." (p. 9)

> "Affordances provide strong clues to the operation of things. Plates are for pushing. knobs are for turning. Slots are for inserting things. Balls are for throwing or bouncing. When affordances are taken advantage of, the user knows what to do just by looking: no picture, label or instruction is required. Complex things may require explanations,

but simple things should not. When simple things need pictures, labels or instruction, the design has failed." (Norman, 2002, p. 9)

Affordances are dependent to some extent on some level of reasoning and this may be an issue for people living with dementia. However, if design builds in affordances to the greatest extent possible and reinforces this by using shapes, colours, textures, smells, or other perceptible characteristics that remind people of previous experiences, then the possibility that people living with dementia will understand how best to use the item will be improved. The design of entrances to buildings is one example of this where a porch or entrance canopy, regardless of detailed design, 'speaks' to a user in a certain way and suggests without explicit instructions that this is the entrance. A covered porch or canopy is a widely used vernacular and almost archetypal architectural feature and will be interpreted by people, whether they are familiar or not with the particular style of canopy, as the entrance to a building. This is not a question of having any prior knowledge per se, but is an example of where the canopy design using affordances, expressing a clear function, and prompting recognition through shape and location to inform people that this canopy marks the entrance to a building (see Figure 11).

Figure 11- A traditional entrance canopy and a contemporary canopy

A balance needs to be struck between the design of everyday dwellings which will be used by a variety of people and design that caters for the specific, complex needs of people living with dementia. Dwellings and objects consistent with Universal Design may greatly benefit families and carers thus reinforcing the caring environment. Indeed if people are introduced to Universally Designed products or features early then these will become familiar to these people and the principles of 'Familiarity' and 'Simple and intuitive' will merge.

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This issue is deemed important enough to retain as originally stated and it will become part of the proposed design guidelines.

4.   Promote and support meaningful activities.

This principle is beneficial to all occupants of a dwelling but as discussed previously it is particularly relevant to people living with dementia, their families and carers because of the importance of maintaining activities of daily living and enabling people living with dementia to remain occupied and stimulated.   The Universal Design goals discussed earlier support the promotion of meaningful activity through the overarching concern for social participation and this is also reflected in the seventh goal for the design of Dementia Friendly Dwellings which states that 'Design should support meaningful activity' (see page 55). Also, since Universal Design principles seek to make things accessible, usable, and understandable to a wide range of users regardless of age, size, ability or disability, all seven principles of Universal Design support this dementia friendly approach.

While this is a very important issue, both the goals and principles of Universal Design already address this.

5.   Provide an environment that is easy to interpret and calm, paying particular attention to the reduction of acoustic and visual disturbances.

A calm environment is important for people living with dementia and indeed for their families including those who are caregivers as well as formal carers. In fact, it can be argued that calmness is an important environmental characteristic for most people. An easily interpreted environment is vital for the reasons already discussed and this aligns with the 'Simple and intuitive' and the 'Perceptible information' principles of Universal Design. As mentioned earlier, people living with dementia may be very sensitive to noise. Judd (1998) emphasises this by stating that "noise to people with dementia is like stairs to people in wheelchairs" (p. 17).

This issue is very important for dementia friendly design and will be included in the design guidance as stated.

6.   Provide good signage and multiple cues to help with way-finding and legibility.

Written and pictorial signage is used in buildings for people living with dementia to make certain uses explicit (e.g. the toilet) and reinforce identity (e.g. names on doors). While this information is visually based, other cues such as sound, smell and touch are also important in terms of orientation which is addressed by the Universal Design principles of 'Equitable use', 'Flexibility in use' and 'Perceptible information'. The latter may also be important for older caregivers who are cognitively intact but are experiencing visual difficulties.

The principles of Universal Design already comprehensively address this issue and therefore it does not need to be reiterated in the guidance.

7.   Provide distinct spaces for different activities.

If certain activities (e.g. eating, cooking or doing the laundry) always take place in the same setting which is also a more defined space, it is thought that this may help reinforce certain patterns of behaviour. One approach may be to create independent and enclosed spaces, based on a more cellular layout. In an open plan layout, it may be enough to define a space using a free standing bookshelf or a hanging light over a dining table, the intention is to create some level of distinctiveness that a person identifies with a particular activity. While 'Flexibility in use' is a Universal Design principle, this also states that such flexibility should accommodate a range of abilities and preferences.

Provide distinct spaces for different activities to enable rooms and areas to be associated with their respective functions.

8.   Provide good visual access to key areas of the dwelling or to important objects to remind and prompt the occupant when required

Although this design approach is dependent on visual abilities, it is nevertheless an important aspect of design for people living with dementia. For example, visual access to the garden may encourage people to venture outside, while a direct view of the toilet may help people to use the toilet more frequently thereby avoiding accidents. It is hoped that principle 6 'Good

signage and multiple cues to help with way-finding and legibility regardless of sensory abilities'
(see page 62) can be employed to help those with visual impairments. While the Universal
Design principle for 'Perceptible Information' covers the issue of visual access to some extent,
it does not emphasise visual access to the extent required for dementia friendly design.

Given the relevance of visual access it is deemed important enough to be included in the
guidelines as a dementia specific design issue as stated.

9. Support personalisation of the environment to enhance continuity of self.

Personalisation is an important part of good design of buildings for people living with dementia
and is included as one of the Universal Design goals. Personalisation is also supported to some
degree by the Universal Design principle of 'Flexibility in use' which facilitates individual
preferences. However, due to the importance of this for people living with dementia, it would
be worth emphasising personalisation as a key dementia friendly design issue.

Figure 12 – Examples of personalised entrances to dwellings

This design issue will be included in the final design guidance as stated above.

10. Provide unobtrusive safety measures to protect from hazards.

As described earlier in this document, safety is one of the main concerns families, carers and
health professionals have when attempting to provide home care and in this context, the
inadequate design of the internal dwelling can pose risks to people with dementia living in their
own homes and indeed to family caregivers if they are frail and older themselves and also to

formal carers. We the researchers would subscribe to an approach called 'positive risk taking' for people with dementia living at home. The latter is a way of balancing wellbeing and autonomy with safety. Depending on the individual, the severity of the dementia and whether he/she lives alone or not, there may be a need to limit access to certain hazards or provide assistive technology to protect that person. While disguising certain controls or exit points may be at odds with certain Universal Design principles, it can be argued that such measures, if handled sensitively, will not be noticeable to a person living with dementia or will not cause frustration. The Universal Design principle of 'Tolerance for error' may be employed here where "design minimizes hazards and the adverse consequences of accidental or unintended actions" (Maki & Topo, 2009, p. 65). Maki and Topo (2009) interpret this principle in the context of design of buildings for people living with dementia and propose that this principle;

> "implies that one should arrange elements to minimise hazards and errors (the most used elements are the most accessible, while hazardous elements eliminated, isolated or shielded), provide warnings of hazards or errors, provide safety features and finally discourage unconscious action in tasks that require attentiveness". (p. 65)

Figure 13- Image 1 shows a services cupboard in the common hallway external to the dwelling. Image 2 shows a curtain that can be drawn across the internal face of a door to hide the exit.

Maki and Topo (2009) argue that due to people with dementia's short attention span, designs should be reliable and work immediately, providing friendly feedback to the user. Obviously, in the case of an emergency such as a fire, warnings need to be robust enough to elicit a

response, but care must be taken not to create any undue confusion or excessive anxiety. This design approach seeks to guide designers or users towards more sensitive solutions for providing a safer dwelling and a more tolerant environment.

AALs are often provided in the context of safety and used to support independent living. Examples include Telecare or safety devices installed within the home like for example flood detectors or sensors that offer occupants protection from potential hazards such as unattended cookers or gas appliances. With this in mind it may be more instructive to bring together safety and assistive technology and to rephrase this design issue as follows;

Provide unobtrusive safety measures and ambulant assistive living devices to provide a safe and secure environment.

11. Provide space and environmental support including ambient assistive living devices to support carers to sustain the caring relationship.

Undoubtedly, the absence of adequate support for family caregivers makes home care less sustainable. While this clause is particularly relevant for designing dwellings for people living with dementia, it is equally important in terms of supporting any occupant of a dwelling who may have specific needs, including older people and indeed young children. The Universal Design principle 'Size and space for approach and use' as presented earlier contains a guideline stating the need to "Provide adequate space for the use of assistive devices or personal assistance" (see page 39). The principle of "Low physical effort" is also applicable in terms of reducing the physical effort required by a carer to assist the person with dementia.

This issue is sufficiently covered in the Universal Design approach and it is therefore unnecessary to include it as a separate issue in the guidance.

12. Provide safe and accessible outdoor spaces which are perceptible from the interior to encourage occupant use of these spaces.

This principle recognizes the importance of spending time outdoors, maintaining contact with nature, being exposed to daylight for Vitamin D manufacture and the regulation of circadian rhythms, and for the continuation of everyday activities such as gardening, taking exercise or

hanging out clothes. Outdoor spaces, like other spaces, are subject to all the principles of Universal Design to ensure they are not only accessible but also usable and easily understood by all people regardless of age, size ability or disability. Figure 14 shows a very safe and enclosed small courtyard space directly adjacent to a dementia friendly dwelling. This not only provides a safe and secure outdoor space but also provides much shelter from the elements.

Figure 14 – External space in the form of an enclosed courtyard in Barn Halt Cottages, Carrickfergus, Co. Antrim

An aim of this principle is to encourage people to use these spaces. Therefore there is an emphasis not only on creating easy access to these spaces, but also on creating awareness of outdoor spaces for a person inside. This could be achieved through enhancing visual access, or channelling sounds (birds chirping), gentle breezes or smells (fruits) into the interior space so that the presence of an outside space, or access to an outdoor space, is more perceptible to those who may not otherwise decide to venture outside. Of course it is essential that these spaces provide a safe, secure environment that may include some level of appropriate enclosure to minimise an accidental contact with hazards that may exist adjacent to the dwelling, such as traffic. This again depends on individual circumstances and the stage of dementia.

In recognition of the importance of spending time outdoors this design issue will be included as stated above.

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Figure 15 brings together the aforementioned design issues that are important when taking a Universal Design approach for dementia friendly dwellings and illustrates their direct connection with the typical home.

Encourage a participatory design approach where people with dementia, carers and other family members can take part in the design process

Familiar design with the use of recognisable features that are consistent with users expectations

An environment that is easy to interpret and calm paying close attention to the reduction of acoustic and visual disturbances

good visual access to key areas of the dwelling or to important objects to remind and prompt the occupant when required

safe and secure outdoor spaces which are clearly perceptible, regardless of sensory or cognitive abilities, from the interior to encourage occupant use of these spaces

Unobtrusive safety measures and assistive technology to provide a safe & secure environment

Personalisation of the environment to enhance continuity of self

Provide distinct spaces for different activities

Figure 15: Dementia friendly design issues

3.4. Conclusion

This chapter introduced the reader to some key definitions and terms, and provided an overview of design principles and goals underpinning a Universal Design approach to dementia friendly dwellings. It then progressed to critically review the contribution that experts such as Lawton (e. g. 2001), Marshall (e. g. 2009) and Calkins (e. g. 1988) have made to the development of design principles and goals. The point was made that most of the literature to date has been mainly concerned with guiding the design of long-stay care facilities for people living with dementia and not designing or retrofitting dwellings where we know most people with dementia live. While most of these design goals and principles can be easily used to guide

the design of general dwellings for those affected by Alzheimer's disease or other dementias, it is argued that a specific set of design principles and goals is needed to underpin the guidelines that are being developed in this study for the design and retrofitting of domestic dwellings for people living with dementia. The goals and principles developed specifically for application to the design of homes for people living with dementia are thus presented.

The next chapter seeks to provide a better understanding of dementia and the obstacles and facilitators to living well with dementia that the home environment poses. The chapter will review the literature on the subjective experiences of people living with dementia in the home. It will discuss some memory and cognitive difficulties experienced by some people diagnosed and the main concerns people living with dementia along with their family members and carers (formal and informal) may have. It will argue that an understanding of the respective concerns of people living with dementia, their families and carers' is necessary if we are to design effectively for the impact of dementia and if we are to use building design to support people to live well and care well in the home.

3.5. Key Recommendations

- The design guidance arising from this research should include the design goals developed in this chapter (see section 3.3.3) in order to inform design professionals and other key stakeholders about the needs and preferences of people living with dementia, their families and carers and to articulate and define the overall rationale for the Universal Design of dementia friendly dwellings.

- The design guidance should also use the eight dementia friendly design issues compiled in Section 3.3.4 to inform the Universal Design approach and provide dementia specific guidelines.

Chapter 4: 'Living in Place' with Dementia

4.1 Introduction

This chapter focuses on people with dementia living in their own homes either with the support of family members who live with them or with the support of family members and carers who live apart. Davis et al. (2009) argue that an understanding of these peoples' experiences in everyday life is important in order to create appropriate physical environments for them. In keeping with this, Section 4.2 of this chapter discusses the everyday experiences of people living with dementia and their families. There is limited evidence available on the subjective experiences of friends, neighbours or care workers providing care and support to people living with dementia in the home, but where this is available it is included. In addition, an understanding of the main symptoms of dementia is also required and this is addressed in Section 4.3. Section 4.4 identifies the most common concerns that families and carers may have about their relative with dementia in the home. The final part of the chapter draws conclusions based on the materials presented.

4.2 The 'lived experiences' of people with dementia, their families and carers in the home

As mentioned earlier, most of the research on the 'lived experiences' of people with dementia has been carried out in relation to dementia-friendly environments in residential long-stay settings. However, an understanding of the lived experiences of people with dementia who live at home and how the physical environment can best assist the person to remain meaningfully engaged in everyday life is useful when designing new homes or retrofitting pre-existing ones.

'Lived experiences' that warrant most consideration include the basic and instrumental activities of daily living, personal enjoyment, and family and social involvement.

Home is a place where many basic activities of daily life are carried out. These include eating, sleeping, washing, dressing and toileting. It is also a place where instrumental activities of daily living such as cooking, household chores, shopping, using the telephone and gardening are carried out. In short, activities that help to maintain health and well-being and that enable a person to live independently. Many of these activities that occupy much of our day are taken for granted, until such time as we can no longer do them and assistance from others is sought. People living with dementia should also be enabled with the involvement of their families and carers to participate in leisure activities based on individual interests and choice (NICE, 2013). Many of these leisure activities can also be facilitated in the home.

In common with most older people in Ireland (Timonen et al., 2011), the type of leisure-time activities that people living with dementia enjoy include watching television, reading books or newspapers, knitting, sewing, doing crosswords and listening to the radio (Begley, 2009). The physical environment can encourage spontaneous personal enjoyment. Phinney et al. (2007: 388) offer the example of Maggie, a person living with dementia, who is quoted as saying:

> "If I'm home alone there, if I remember, I'll go and try and even, I don't care what it is, just play something on the piano".

Dementia has a direct bearing on activities of daily living and research has shown how many people living with dementia find mastering their activities of daily living and managing the home increasingly difficult because of the condition (Nygard and Ohman, 2002; Phinney, 2008). Some worry that they might eventually lose the ability to do these tasks (Phinney, 2000). As a result of impaired executive function, routine activities such as sorting the post, lighting the fire, or adjusting the thermostat can take longer and have the effect of slowing down the pace of everyday life (Phinney and Chesla, 2003). Operating the cooker and other cooking utensils can make mealtime troublesome for persons with dementia living in their own household. Inability to manage such tasks may lead to poor food intake or even malnutrition (Johansson et al., 2011). These same activities can also raise concerns about safety particularly if the person has a more moderate to severe dementia.

Despite experiencing some difficulties in daily living, most people living with mild to moderate dementia continue to do what they can in order to maintain their independence and to remain involved in everyday tasks (Phinney, 1998). One small-scale, qualitative study looking at meaningful activities from the perspective of people living with dementia found that study participants engaged in activities that they felt were important to them. For some these activities were a central driving force in their lives. Carrying out housework at home was shown to be extremely important and when asked how they spent their days, people living with dementia spoke enthusiastically about making their beds, helping to prepare meals, washing dishes, ironing, vacuuming and gardening (Phinney et al., 2007). Although people living with dementia did not always find these household chores easy, they rarely or never spoke about giving them up. Rather, they emphasised how important it was for them to be able to continue doing such activities, even if sometimes it meant they had to create different strategies or change their ways of performing these tasks to compensate for memory loss (Johansson et al., 2011; Phinney et al., 2007).

In an Irish study, Meaney et al. (2005) found that doing housework, including the laundry, using the cooker and heating, were all activities that were generally manageable within the homes of most people living with dementia. For example, only one-fifth of those in their study experienced difficulties using the cooker and heating. Sometimes these people required assistance from families and carers (Phinney, 2006; Begley, 2009). Indeed it is possible that such activities were manageable because they were carried out by or with the assistance of family caregivers. In another recently completed Irish study, findings showed that the activities undertaken by family caregivers prior to the admission of their relative with dementia into residential long-stay care were wide-ranging and included basic activities of daily living (dressing, toileting, showering, administering medication) and instrumental activities of daily living (grocery shopping, cooking, , laundering, organising doctor appointments). In some few cases activities undertaken by family caregivers also extended to home maintenance including repairs (Bobersky, 2013).

Apart from home being a place where basic and instrumental activities of daily living and sometimes leisure-time activities are carried out, home is also a place where people can store their possessions such as pictures, trophies, and other such mementoes. These same possessions are often associated with memories, which can help to reinforce peoples' self-identity (Cram and Paton, 1993). Possessions can also contribute to the personalisation of

space by enhancing feelings of control of the environment, increasing self-confidence and providing feelings of security (Hemmingway, 2011). Being surrounded by familiar and treasured items is important to people living with dementia (Innes et al., 2011). Indeed the personalisation of the environment today is strongly encouraged in policy documents and endorsed for example in standards for residential care settings in Ireland (HIQA, 2009). Family caregivers are often motivated to help their relative remain in their own homes since they too believe that being in a familiar environment, surrounded by shared memories, and treasured items provides them with a sense of security and belonging, factors known to contribute to a good quality of life (Lundh et al., 2003). In the recent Alzheimer Society of Ireland consultations with people living with dementia and their family caregivers several participants talked about the factors that helped sustain them at home for longer (Easton, PC, 2014). When people living with dementia and their families are at home surrounded by their personal possessions such as family photographs, mementoes and books, it helps formal carers visiting the home to be more aware of the uniqueness and individuality of the people living there and makes it harder for them to view the people living with dementia as simply an object that needs care (Twigg, 2000).

People living with dementia enjoy being surrounded by their families and friends and welcome continued contact with them as this provides an important opportunity for social involvement and meaningful interactions with other people. It also enables them maintain and develop relationships, one of several quality statements embedded in the NICE Standards for supporting people to live well with dementia (NICE, 2013). Simply spending time with family members and enjoying the companionship of being with a loved one is a positive feature of home life (Phinney et al., 2007) and the home environment is a place where such family bonds and relationships can be fostered. Family caregivers of people living with dementia consider that the close contact their relatives have with family and friends, as afforded within the home environment, contributes to a feeling of belonging and continuity (Lundh et al., 2003).

Indeed based on their research, Phinney et al. (2007: 391) suggest that 'providing opportunities for personally meaningful activity should be an important aspect of dementia care, not only in facilities, *but also in people's homes and communities'* (Italics added). They maintain that continuing 'usual' activities, can give people living with dementia a sense of personal autonomy, reinforce personal identity and foster a valued social role (see Phinney et al. 2007: 289-90). In addition, engaging in usual daily activities may have other positive impacts.

Studies have shown that even in long-stay residential care settings like Specialist Care Units where the physical environment is arranged like a typical home, where rooms are personalised and where residents can engage in domestic activities, people living with dementia experienced less decline in their activities of daily living, less anxiety and improved motivation compared with those residents living in traditional nursing units (Reimer et al., 2004). However, it needs to be remembered that changing the physical environment does not automatically lead to increased activity for all people living with dementia. Some will find the home environment isolating, uninteresting and may have trouble way-finding and finding things to do at home to keep them busy (Phinney et al., 2007).

Apart from engaging in leisure-time activities at home, many people living with dementia want to and enjoy going out. Many like to take part in social activities outside the home and such activities can contribute to well-being and a better quality of life (Duggan et al., 2008; Phinney et al, 2007). Others, according as their cognitive ability declines, may adapt to moving within a gradually smaller area and may sometimes stop going out altogether (Duggan et al., 2008). Spending more time at home because of dementia or because of its progression means the comfort, aesthetics and warmth of the home all take on greater significance (Heyman, Oldman and Means, 2002). This is very salient when developing a Universal Design approach for dementia friendly dwellings since standards of design in the home including air quality, temperature, lighting internal space and the design of the immediate surroundings can all influence the physical and mental health of those living there (Lavin et al., 2006).

Most of the literature on the lived experiences of people with dementia at home focuses on those with mild to moderate dementia, with far less attention paid to those with more advanced dementia. As dementia progresses, changes in people's ability to remember, understand, communicate, undertake new learning, behave rationally and negotiate their way in a three dimensional world, can further challenge their capacity to live at home. The rate at which dementia progresses varies for each individual, but as the condition progresses, and according as other age-related co-morbidities such as arthritis, cancer, heart disease, diabetes or sensory impairments may manifest, the person will generally need more support to help manage their day-to-day activities. For example, they may need frequent reminders or help to eat, wash, dress and use the toilet. Eventually, as dependency needs increase, the person living with dementia will gradually become totally reliant on others. In one Irish study, Meaney et al. (2005) found that bathing and self-washing were the most frequently identified unmet needs of

people living with dementia. Not surprisingly, those with more advanced dementia and those living alone generally experienced more difficulties in undertaking activities of daily living.

It is generally assumed that most people living with dementia want to continue to live independently in their own homes for as long as possible and want to live as normal a life as they were having prior to getting a diagnosis of dementia (Diaz, 2014). While it may be possible for some to remain at home, even as the dementia progresses, there comes a time when due to the level of care required, the only feasible option is residential long-stay care. The reality is that most people living with dementia do not live out their last days at home (Keene *et al.,* 2001; Mitchell *et al.,* 2005), even though most would prefer to die at home. Moreover, there is a dearth of literature on the experiences of community dwelling people with dementia or their families and carers leading up to the last days of life and on what supports are needed or what inhibits end-of-life care at home (Goodman *et al.,* 2010).

The individual's well-being, his/her ability to master activities of daily living and the physical environment are all closely intertwined (Zarit and Leitsch, 2001) and the PLwD can never be separated from the physical environment in which he/she carries out these activities. Phinney et al. (2007: 391) argue that supporting people living with dementia to engage in meaningful activities is a matter of creating not only a social environment but also a physical environment which provides natural cues for familiar activities; is responsive to the fluctuating demands of everyday life and allows activities to happen in a spontaneous and flexible way.

Figure 16: Everyday activities such as mowing the lawn can be an important meaningful activity.

It is increasingly recognised that the design of buildings can be either enabling or disabling for those who use them (Judd et al, 1999) and that environmental factors can have a significant impact on health (IPH, 2006; Tinker, 2014) and on independence, functionality, ability to be socially active, and hence on quality of life (WHO, 2011). In this sense, the home is viewed as an occupational space and it is the use of space as opposed to design features that are important to people living with dementia (Innes et al., 2011). The example cited by Phinney (2007: 388) where the piano is located at home in the kitchen illustrates how familiar spaces and objects can be used to solicit involvement by people living with dementia and can act as cues for activities that have always brought pleasure and enjoyment.

Much of how we think about ourselves is reflected in our home environment and it is the same for people living with dementia and their families. Even if one's perception of time and space has become distorted because of dementia, the home and the relationships, activities and objects within it, often continue to remain very salient for the individual. Just as the quality of the social environment can impact on the experiences of people living with dementia, the quality of the environmental design of the home can also be important. People with dementia should live in housing that meets their specific needs (NICE, 2013) and it is argued that by adapting the built environment the individual's well-being and functioning will be enhanced and that person can be helped to live at home longer. Naturally no two people will have the same

subjective experiences of dementia and likewise no one particular house will suit all people living with dementia. Each person is unique and will experience dementia in a different way and peoples' individual perceptions and wishes are also important. Therefore, there is a need for the physical home environment to be able to meet differing needs and preferences of the people with dementia and family members living there with them.

For formal carers the person with dementia's home is their place of work, but unlike formal carers working in residential care settings, they are only there for part of the day. Twigg (2000) in discussing the spatial ordering within the home, describes how certain areas of the home are public, relatively open to visitors, whilst others are private, generally used only by those who live there. She highlights the challenge this presents for formal carers who recognize the space as belonging to residents. As one formal carer interviewed by Twigg explained:

> '… you're going into a … person's home, and even if they ask you to make a cup of tea … you don't know where the cups are and you don't know where the sugar's kept, and it's sort of like you're in there in somebody's house as a worker…'

Since the home has not been designed as a workplace, many of the environmental factors that affect people living with dementia and their families will no doubt also impact on formal carers and these will be discussed in more detail in Chapter 5.

4.3   Understanding dementia: designing for its effects

This chapter takes a person-centred approach and has deliberately opened with a discussion of the lived experiences of people with dementia and their families to remind the reader of the salience of the individual and the real difficulties and challenges that a person and their family will confront coping with the symptoms of dementia whilst living at home. However, designing new builds or retrofitting dwellings for people living with dementia and their families and carers requires not only an appreciation of these peoples' subjective experiences but equally some recognition that dementia is an organic illness and a disease which for the most part is progressive and incurable. It also requires an understanding of the symptoms most commonly experienced by people living with dementia, and recognition that any design solutions need to offset the effects of the condition.

Impairments associated with dementia can have severe and adverse implications for a person's quality of daily life and for their independent functioning. Since the built environment can compensate for the impairments/difficulties associated with dementia to a greater or lesser extent (Marshall, 2001), specially planned or easily adaptable dwellings are often needed for people living with dementia. The section to follow will now explore in more depth facts about dementia including its main symptoms. It will also explore some of the behaviours people living with dementia are likely to exhibit which can challenge families and carers.

Dementia has no single cause and while there are some common identifiable symptoms, how the individual experiences dementia is unique and is related to the subtype (Alzheimer's Society, 2011) and to other factors, environmental and otherwise, including other illnesses which may superimpose the dementia. The most common types of dementia are Alzheimer's disease, Vascular Dementia, Mixed Dementia and Dementia with Lewy Bodies. However, many different diseases cause dementia and the less common types include the fronto-temporal dementias such as Pick's disease, Korsakoff's disease (alcohol related dementia), Huntington's disease, Creutzfeldt Jakob disease (CJD) and AIDs-related dementias.

Despite these different diseases, causes and experiences of dementia, it is argued that from the point of view of designing for dementia 'the differences are not as important as the similarities' (Calkins, 1998: 4). The symptoms of dementia almost always include:

- difficulty remembering things, especially recent memory
- problems with new learning
- impaired reasoning, judgement, and problem-solving, that is, the capacity to work things out
- increasing dependence on the senses
- increased anxiety and stress

Increasing age is by far the strongest risk factor for dementia and the risk of developing dementia doubles about every five years after the age of 65 (Lobo et al., 2000). In addition to cognitive difficulties, as mentioned earlier, other age-related changes that people living with dementia may experience include:

- impaired mobility leading to increased risks of falls.
- vision and hearing loss.
- impaired ability to communicate.

4.3.1 Cognitive difficulties

As dementia progresses, parts of the brain will become significantly impaired and will cease to function whilst other parts will continue to function well. Accordingly, good design should seek to not only compensate for impairments but to also build on the retained abilities and the strengths that people still have (Marshall, 2001; Timlin and Rysenbry, 2010). As Zeisel (2006: 271) argues, 'well-designed physical environments for people living with dementia substitute for missing capabilities while directly supporting remaining skills'.

A main symptom of dementia is memory loss, particularly short-term memory, and many people will be unable to recall everyday recent information. Just as people living with dementia might struggle to remember a name, fact or an event, they often find it difficult to remember how to negotiate their way around physical environments and buildings. Remembering a fact or event is made easier when the person is prompted by a reminder or a memory aid, often referred to as recollection. In the same way, external memory aids such as signage or cues can be used in the home and external environment to remind people living with dementia where they are.

In addition to memory impairment, a person living with dementia will have impairment in at least one other cognitive function which is sufficiently severe to cause significant problems to social or occupational functioning. Damage to the parietal lobes, for example, can result in the loss of spatial processing abilities and memory and the latter can pose a major environmental challenge to the individual. In familiar settings, people living with dementia can often manage to find their way about for a long time, although way-finding becomes more difficult as the dementia progresses. Whilst most people with mild dementia and the vast majority with moderate dementia can find their way around the home unaided, research has found that less than half (42%) of those with severe dementia can do so independently. One study showed that 42% of the latter group, needed some cueing and 17% were completely dependent on others for navigation (Marquardt et al., 2011). This is consistent with findings from long-stay residential care settings (Marquardt & Schmieg, 2009).

Research that has been undertaken in long stay residential care settings has shown that it is possible that modifying the architectural design and the layout of the dwellings could enhance way-finding for people with severe dementia. Marquardt et al. (2011) suggest this could be a focus of future research on home modifications for people living with dementia. As the latter are better able to negotiate environments that edit out difficult way-finding demands, one of the aims of dementia-friendly design at home is 'to make sure that even if the person with dementia forgets where things are they can easily find them' (DSDC, 2010: 34). Therefore, clear spatial landmarks in the home are important (Zeisel, 2006). As people living with dementia have difficulty remembering a visual map, information required to find one's way around the home needs to be self-evident or *naturally mapped,* that is, embedded in the house rather than needing to be kept in mind (Zeisel, 2006).

Familiarity as mentioned earlier is an important factor supporting the continued involvement in everyday activity by people living with dementia (see Phinney, 2007: 390) and it is important to surround the person with dementia with familiar items and provide clues for the individual to help work things out. A person should never have to rely on new learning with respect to the built environment, for example, where to locate the kitchen or bathroom and it should not be necessary for that person to apply reason. For example, kitchen appliances such as cookers, fridges and microwaves should be familiar and have very simple controls. Arising from this, it has been argued that making substantial changes to the person's physical home environment should be avoided (Marshall, 2010).

The frontal lobes of the brain have responsibility for our executive functioning which determines our ability to initiate activities, plan and sequence events, comply with social norms and mores and provide accurate feedback to ourselves that what we are doing is correct. It also refers to 'the thought processes that allow the brain to co-ordinate simple actions to complete a more complex outcome' (Wilcocks, 2010: 57). Dementia can affect the individual's executive functioning. Accordingly, performing tasks such as dressing or preparing a meal, setting the table, making the bed, which involve several different steps, can be difficult as this involves a complex process of organisation. However, procedural memory, i.e. memory of how to do things without having to think, is often retained for longer and is a strength that can be built upon.

People living with dementia may be able to carry out certain activities based on old habits and embodied routines (Nygard, 2004). In this context, performing mealtime tasks offers a good example. While not everyone with dementia can manage mealtime tasks independently, some people (mostly women) continue to be responsible for the household cooking despite their memory loss (Johansson et al., 2011). Memory is also about remembering and knowing what will or what is about to happen. Prospective or planning memory is about remembering and deciding on future goals as well as recalling what is needed to reach that goal. For people living with dementia, the ability to remember future events is lessened and might explain why they are less likely to do things on their own. People living with dementia also tend to retain their sense of smell, touch and hearing and many compensate for their dementia by placing increased demands on their senses. The environment can be designed to take advantage of this so that people living with dementia can use different senses and will not have to rely only on one sense. Non-verbal messages and cues, for example, can be used as can smells of food to indicate time for eating.

High levels of stress and anxiety can be common in people living with dementia and can impair their ability to function. People living with dementia may not be able to process or block out multiple forms of conflicting information or stimuli so that the layout of the building and individuals rooms needs to be carefully and creatively considered to ensure that stimuli are appropriate, clear and controllable. Therefore, it is important to control unnecessary stimuli and tailor environments to the needs of individuals. Buildings that are not naturally mapped can be upsetting, frightening and create anxiety for people living with dementia (Zeisel, 2006).

4.3.2 Mobility difficulties

Physical difficulties can sometimes affect people who have dementia and their ability to perform household tasks (Johannson et al., 2011). Mobility problems can be alleviated by the use of grab bars to enable the person to move about the home. Other mobility aids such as a cane, walker or wheelchair can also be used inside the home. Lack of handrails, uneven walking surfaces, and room sizes are all features of the home that can impede people living with dementia or family members who may have physical impairments. A US study found that families often modify the homes of people living with dementia to compensate for physical limitations. The most common modification is to enhance bathroom safety, whilst others

include installing a lift, putting a handrail on stairs and moving the bedroom downstairs (Marquardt *et al.,* 2011).

4.3.3 Visual and auditory difficulties

As people age they are at an increased risk of age-related changes to vision, so inevitably a number of people living with dementia will also experience visual difficulties, as will older family caregivers. Jones and Trigg (2007) estimated that about 2.5% of people over the age of 75 are likely to have a dementia accompanied by significant sight loss. This estimate is conservative as it is believed that sight loss is more prevalent in people with dementia than in cognitively intact older people. Age-related changes to vision include blurred vision, and tunnel vision and the need for more light in order to see properly. A problem for people living with dementia is that they are often unable to understand or communicate that their eyesight is failing and are unable to take action to compensate for this (Marshall, 2010: 61-62). In most cases, dementia and sight loss develop independently, but others may experience other visual difficulties including problems with depth perception, which make it harder to identify objects that are set against a background consisting of similar colours; diminishing ability to distinguish between different colours; increased sensitivity to glare; and visual misinterpretation (Bakker, 2003). These problems are believed to be more indicative of difficulties in processing visual information due to perceptual disturbances in the brain as opposed to any specific problem in the eye or the optic nerve (Trigg and Jones, 2005; Jones and Trigg, 2007). One qualitative study found that the combined experience of dementia and sight loss created a profound sense of disorientation in older adults. The latter also restricted participation in hobbies and social groups, and visual hallucinations were not uncommon (Lawrence et al. 2008).

Noise as mentioned earlier is a known cause of stress for people with dementia, According to Bakker (2003: 48):

> "People with dementia may have normal hearing, but they can lose the ability to interpret what they hear accurately. Underlying hearing disorders can also predispose a person to auditory hallucinations … Excess noise can result in confusion, overstimulation, and difficulty communicating".

Some people with dementia, however, will have age-related hearing loss (Bakker, 2003).

4.3.5 Sleep difficulties

Sleep disturbance is common in people living with dementia for a variety of reasons including medications, physical problems, social settings, cat napping during the day and psychological considerations (Pollock and Pollock, 2010). The individual's circadian rhythms may be adversely affected leading to insomnia, nocturnal restlessness and wandering. One study showed that people living with dementia were more likely to be placed in long-stay residential care due to nocturnal restlessness than because of memory or cognitive problems (van Hoof, 2009). Natural daylight is important for people in setting their body clock, as it is the body clock that sets the normal rhythms in a day, including going to sleep or getting up (See DSDC, 2010).

4.4 Family caregivers' concerns about people living at home with dementia

Family caregivers in Ireland want to care (O'Shea, 2004) and the majority wish to help their relatives diagnosed with dementia to remain living at home for as long as possible (Cahill et al, 2012). However, there is limited literature on the topic of family caregivers' and their perceptions of how suitable or otherwise the home environment is for caring when a relative develops dementia and as the illness progresses. In the Alzheimer Society of Ireland 2013 roundtable discussions with carers, some spoke about the need for better services to help them maintain their relatives at home (ASI, 2013). It was reported that it was only when a crisis arose that several caregivers received any assistance and by then it was probably too late. Some mentioned the importance of ensuring that their relatives maintained their social circles and their hobbies. However, this often presents difficulties as friends and support networks are unsure as to how to respond to dementia (ASI Roundtable Meeting, 2013).

Environmental safety has been found to be one of the most prevalent areas of need for those diagnosed with dementia who endeavor to live at home (Johnston et al., 2011:3) and, as dementia progresses, safety needs become a heightened concern for many families. Wandering away from the home or getting lost, falling, being scalded and other domestic risks associated with for example cooking have been identified by families and health service professionals as key concerns especially when people with dementia live alone (Gilmour et al.,

2003). A recent exploratory study by Bobersky (2013) revealed similar safety concerns by Irish family caregivers[10].

A person living with dementia may feel compelled to go outdoors and leave their home unaccompanied - an activity often labelled as "wandering". Marshall (2001: 127) argues that wandering is a misleading term as she argues that it is usually an activity that is purposeful, even if the purpose is not clear to those observing it. She posits that a wide range of reasons exist to explain why people living with dementia might 'wander'. These include the continuation of an old habit such as taking regular exercise, the relief of boredom, pain or discomfort, using up excess energy, a response to anxiety or memory loss, a desire to search for the past, to seek fulfilment, or simply these people because of their dementia may want to go outdoors as they are disorientated in time.

'Wandering' can be worrying for families, carers and health service professionals responsible for providing services to people living with dementia, especially if the person is prone to going out to unsafe places at anti-social times and placing himself/herself at risk. Keeping a person with dementia safe and reducing the risk of their wanting to leave the home is a common concern associated with caring for a person with dementia in an environment that is not well adapted (Fleming, Crookes and Sum, 2009). Property exit sensors are one solution sometimes used (Connolly, 2011) but as in the case of all assistive technologies, such interventions must be used in an ethical manner.

For the person prone to moving around like this, The Alzheimer Society UK recommends finding a solution that enables the person walk about safely. Sadly, some family caregivers have had to resort to lock or bolt doors to prevent the person with dementia from leaving the house in an attempt to keep the person safe (Bobersky, 2013):

> "His bed was upstairs all the time and he didn't want to move down … Mum would lock the back door if she went out somewhere and he'd get out through a window … and we were afraid as well that some night he could think he was on the ground floor and go through the window upstairs (nephew carer aged 56).

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[10] For illustrative purposes, some relevant quotes from Bobersky's thesis have been included in this chapter.

Such practices are not recommended. Indeed in some Scandinavian countries legislation exists prohibiting such inappropriate and inhumane practices. We would argue that a person living with dementia should never be locked at home either alone or with others.

The literature suggests that "wandering behaviour" sometimes known as pottering with a purpose (Robinson et al., 2006) is often an expression of unmet needs (Cohen-Mansfield, 2001). Simple interventions such as that of distraction or deterring the person from leaving the house can be introduced. The latter might include disguising the front door (e.g. by fixing a bead curtain across it or painting the door the same colour as the surrounding walls) approach is to ensure the outside area is kept safe and secure so that the person can walk outside without being harmed. This may be done by carefully disguising gates or building high walls with interesting greenery or plants to distract the individual.

Other solutions as mentioned earlier include the use of assistive technology or TeleCare. Although it is beyond the scope of this report to review the extensive literature addressing the topic of assistive technology and dementia, suffice is to say that such technologies have a key role to play especially in the context of designing new buildings for people living with dementia. One of the key findings from The ENABLE project, which was funded by the European Commission under the "Quality of Life and Management of Living Resources" programme and involved five partners countries (England, Ireland, Finland, Lithuania and Norway), was that many of the technologies installed through this project to help people living with dementia maintain their independence might have been more successful had they been more familiar with the technologies from an early stage (Hagen et al, 2004).

A recommendation was that all homes should in the future be equipped with devices that might promote more independent living and protect people from accidents likely to occur at home because of dementia. The ENABLE project demonstrated that many of the technologies installed and trialed in the homes of people living with dementia were equally beneficial to family caregivers as they were to the individual diagnosed with dementia. Technologies tested including a night and day calendar to help orient people to the time of day, a night lamp to assist the individual get to and from the bathroom, an item locator and a cooker switch-off device. Although the items tested were merely prototypes, they were shown to be effective in promoting independence for some people at certain stages in the course of the illness.

Falling is another common concern, families, carers and health service professionals have when people with dementia continue to live at home. In Boberksy's research, one of her participants, an elderly carer, expressed serious concerns about her husband (who had dementia) and who was prone to falls at home. She said: "He could slip on the bathroom floor and break his hip or something, falling on the floor and hurting himself." Impaired cognitive function can also cause mobility difficulties and can result in falls. Marquardt et al. (2011) reported that 57% of the people living with dementia in their study, reported at least one fall in their home within the previous two years. Most of these falls occurred in the bedroom (26%), followed by the living room (17%) and the bathroom (12%). Another 12% of the reported falls occurred at the entrance or in the hallway near the home entrance, and 11% occurred on steps. Marquardt et al. (2011) found that the absence of handrails posed a significant problem. Not surprisingly, stairs (including poor step design, edges or nosing not clearly defined, inappropriate and/or inadequate handrails for support) were among the many hazards facing people with dementia living at home (Brawley (2001).

Others environmental hazards identified by Brawley (2001) include:

- lighting: ranging from too little illumination producing dim or dark surroundings, uneven illumination that creates shadows, uncontrolled glare and unsafe transition areas.
- acoustics: uncontrolled noise, lack of acoustical materials for sound absorption and noise control.
- bathrooms: slippery tub or shower, lack of grab bars or poorly positioned supports, inadequate lighting, no light in the shower.

In terms of safety and in the context of people living with dementia in their own homes, other concerns relate to fire and flood. Due to short-term memory loss, people living with dementia may put the gas on, forget they have done so and omit to light it. Agnosia, or the inability to recognize objects for what they are, means that some people living with dementia may place empty pots on the cooker or turn on water taps or a clothes iron. They may later forget to turn them off (Marshall, 2001). Simple switch off devices can help provide a solution to this problem.

Bobersky (2013) found that safety concerns were for some family caregivers the key reasons why they discontinued home care and why they opted to move their relatives permanently into

long stay residential care. The inappropriateness of the physical environment because of safety concerns was evident in some of the qualitative data:

> "The main reason for [placement in a nursing home] was fear about the stairs" (niece caregiver, aged 43)

> "Daddy had an open fire as well and a range, it was dangerous for Mummy"

Gilmour et al. (2003) identified two main preventative factors which minimise harm. The first was observations on the part of people known to the person living with dementia who were able to put the risk in context, and the second was the levels of contact by others (family members, care staff or neighbours) in the day-to-day lives of the person living with dementia. Designing or modifying dwellings to reduce risk can be considered as another preventative measure. For example, the installation of handrails in hallways and the judicious placement of grab bars in rooms apart from within the bathroom may be an inexpensive way to increase safety and reduce the risk of falls (Marquadt et al., 2011).

The challenges that wandering behavior poses have already been discussed but a major theme to emerge from Bobersky's (2013) work was that family caregivers often had difficulties dealing with a variety of complex changes in their relatives' behaviour such as paranoia, agitation and hallucinations. Some family caregivers had real difficulties when their loved ones engaged in activities viewed by them as potentially dangerous. For example, one family caregiver gave the example of her relative who lived alone and who became preoccupied with cramming the fire with turf in an obsessive and compulsive manner. In this case the person living with dementia may not have realised that there was already sufficient turf in the fire. Most of the family caregivers in Bobersky's study lived apart from their relatives and were essentially running two homes. Her findings showed that in some few cases, people living with dementia may have continued to remain living at home if sleeping arrangements were adapted to downstairs and if other appropriate design interventions had been introduced earlier (Bobersky, 2013).

Moving away from Irish based studies, the international literature has consistently shown that both caregiver burden and the stress associated with attempting to deal with challenging behaviours are important factors leading to the relocation of people living with dementia from their own homes into long-term residential care (Vernooj-Dassen et al., 1997; Thomas et al.,

2004). It is interesting that some of the behaviours that cause family caregivers stress may actually stem from a poorly designed environment. For example, anxiety as experienced by people living with dementia may be precipitated or heightened if the person fails to understand where he/she is or has no recollection of how to find significant rooms at home or exit and entry doors. Anxiety can also be heightened if the environment is noisy (Pulsford and Thompson, 2013). Likewise, because of the design of the individual's home, incontinence may be caused by the individual's inability to find the toilet at home and on time. Modifying dwellings through posting signs on doors such as 'bathroom' or 'kitchen'; reducing excessive noise or creating dwellings which induce tranquil calm environments are examples of other simple interventions that can make a difference.

In an earlier chapter in this report (see Chapter 3) reference was made to positive risk taking. A useful definition of risk is 'the probability of an event occurring combined with the magnitude of losses or gains that would be entailed' (Douglas, 2000: 2). Based on research carried out in residential care settings, buildings which prioritise safety and health have been found to have a negative impact on quality of life of people living with dementia (Torrington, 2007) so positive risk taking in the context of dementia should be recommended. As Clarke et al. (2011: 18) point out:

> "this (positive risk taking) provides a balanced definition of risk which helps us to see the attractions of taking risks (such as personal fulfilment, challenge, excitement) as well as the common understanding of risk as something that suggests danger, harm and threat".

The term 'positive risk taking' has been developed to ensure that when assessing risk the wellbeing and autonomy of the person living with dementia is taken into account explicitly as well as focusing on any need for protection from harm (Clarke et al., 2011). Positive risk taking would be a useful guiding principle underpinning the national guidelines being developed as part of this research. This principle underpins existing guidance on designing homes for people with dementia (DSDC Stirling, 2010).

4.5 Summary

In summary, this chapter has argued that an understanding of the lived experiences of people with dementia and their families and carers at home is important for creating Universal Design

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approaches to dementia friendly dwellings. This is because the physical environment can play a key role in supporting a person living with dementia to remain engaged in meaningful occupations, stay in close contact with family and friends, provide a sense of security, continuity and belonging and ultimately contribute to a good quality of life. Apart from supporting people with dementia to live as independently as possible, dwellings need to be designed to support families and carers who are often helping people living with dementia to remain at home and achieve a good quality of life. At the same time, however, families and carers often express concern for the safety of people living with dementia and family caregivers sometimes find it difficult to deal with changes in behaviour. Their fears and concerns need to be taken into account in the Universal Design of dementia friendly dwellings. A key argument put forward in this chapter is to make 'positive risk taking' a critical guiding principle underpinning the Universal Design of dementia friendly dwellings.

Listening to the views of family caregivers about what aspects of home dwellings work and what cause problems is very important in order to create dementia friendly dwellings from a Universal Design approach. However, the Universal Design of dementia friendly dwellings needs to take into account the needs, lived experiences, concerns and preferences of both the person living with dementia and their family caregivers. In this context, it is important to recognise that differences may exist between those family caregivers who share the dwelling with their relative and those who are living in a separate dwelling. There is a dearth of information available on the views of formal carers about the home dwelling and the impact of its design on their role of caring for people living with dementia at home and it would be interesting and useful to undertaken research on this topic.

This chapter has shown that most people living with dementia want to continue having a normal life and one that they are accustomed to despite their being diagnosed with dementia, a desire shared by their families. This chapter has outlined the main symptoms of dementia and shown how the latter can interfere with the individual's attempt to continue with their life as usual. The chapter has shown that certain behaviours may place the individual and others at risk of harm. It has also shown the way in which other sensory difficulties may further aggravate the subjective experience of dementia and adversely affect quality of life. A case in point based on the literature is the combination of visual difficulties and dementia but equally, hearing difficulties and dementia must further isolate people. This understanding of the main symptoms

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of dementia is critical to designing appropriate environments for those experiencing the illness as the built environment can be used to compensate for memory, cognitive, mobility or sensory difficulties and ameliorate behavioural changes. In doing so it can enhance the person with dementia and their family caregivers chances of living well with dementia.

4.6 Key Recommendations

- Include in the design guidance document accompanying this report an outline of dementia and its symptoms, with an emphasis on the role that Universal Design can play in minimising the effects of dementia and age-related difficulties.

- Emphasise the importance of designing dwellings from a Universal Design approach that can support people living with dementia to make use of their remaining skills and continue as far as possible to live in a way that they are accustomed to and engage in meaningful occupations and relationships.

- Listen to people with dementia, their families to get a better understanding of how they want to live their lives in the home, what aspirations and concerns they have, and to hear from them and from formal carers coming into the home what aspects of the design of their dwelling works and what causes problems for them.

- Adopt 'positive risk taking' as a critical guiding principle underpinning the Universal Design of dementia friendly dwellings.

Chapter 5 – The external and internal design of the home

Croftspar, Glasgow © Andrew Lee

5.1 Introduction

This chapter draws on literature on design, building and adapting dwellings for people living with dementia, their families and carers. Where evidence is lacking, the information is supplemented by that obtained from expert opinion as reported in the literature. The structure of this chapter follows the order of the guidance sections of the Draft Universal Design Guidelines for Homes in Ireland. The main aspects of a typical dwelling are classified into five sections as follows:

- Home Location and Approach.
- Entering, Exiting and Moving about the Home.
- Spaces for Living.
- Interior Design.
- Internal Services and Elements within the Home.

By starting with the outside of the home, then moving to the inside, and finishing with more detailed references to internal services, material in this chapter should be read in conjunction with both the booklets in the 'Buildings for Everyone: A Universal Design Approach' series and the 'Draft Universal Design Guidelines for Homes in Ireland'. Both booklets have been published by the Centre for Excellence in Universal Design at the National Disability Authority. Section 5.4 examines each aspect of a typical dwelling to highlight design features that will support the Universal Design of dementia friendly dwellings. Each section also contains

references to appropriate sustainable design features that are specific to people living with dementia, their families and carers.

It is worth noting that in comparison to residential care settings, the physical environments of homes are diverse, more personal and less controlled (Gitlin, 2003) and therefore can present certain challenges to formal carers entering, looking after and caring for people living with dementia in the home. Homes vary widely in their location, size, physical characteristics and condition. Many of the design features that affect people living with dementia and their families will no doubt also impact on formal carers. Environmental conditions that can affect the provision of care (both informal and formal) in the home include spatial layout, accessibility, lighting conditions, noise levels, temperature levels, air and water quality, sanitation and the overall condition of the home (National Research Council, 2011). Space issues can be very important, as a cluttered home or insufficient space can make it difficult for caregivers (both informal and formal) to provide care (Sanford, 2010). Floor surfaces can make a difference; carpeting can hinder a formal carer attempting to assist a person living with dementia with a mobility aid to move about the home.

This research is being carried out to support Universal Design guidelines for both existing and new dwellings. Adaptations to existing dwellings can range from very minor alterations to major structural changes where a house is 'gutted', or possibly a new extension is constructed. In scenarios involving new extensions or comprehensive refurbishment, it may make sense to treat these as a new build project and adhere to the same design standards adopted for new dwellings. Similarly with a new build project, the location, site conditions, budget, or specific residential needs, will dictate the extent of dementia specific features that are achievable. Therefore this report argues that all design issues should at least be considered in new build and retrofit scenarios as part of the design process. This should involve all dwelling occupants including families, carers and along with other key stakeholders.

In light of this, the design guidelines resulting from this research will not be overly prescriptive, but will instead inform and support an innovative and flexible design approach to providing Universally Designed dementia friendly dwellings regardless of the dwelling type, whether it is existing or new. For these reasons, Sections 5.3 to 5.9 which follow, do not generally make a distinction between the adaption of existing dwellings and the design of new dwellings. Most of the design issues discussed may be appropriate in both retrofit and new-build scenarios and

should therefore be treated accordingly. However, to ensure that any specific issues associated with existing dwellings are addressed, Section 5.10 reflects on the design approach outlined in Sections 5.3 to 5.9 in the context of adapting existing dwellings.

Before addressing each aspect of the dwelling in detail, Section 5.2 briefly outlines the key issues around the Universal Design of dwellings as outlined in the 'Draft Universal Design Guidelines for Homes in Ireland'. Section 5.3 selects a range of sustainable design issues specific to the Universal Design of dwellings for people living with dementia, their families or carers.

5.2   Universal Design of Dwellings

As discussed in Section 1.9, the Universal Design Guidelines for Homes in Ireland concentrate on four key design principles. These call for a Universally Designed home to be: 1) Integrated into the neighbourhood, 2) Easy to approach, enter and move about in, 3) Easy to understand, use and manage, and 4) Flexible, cost effective and adaptable over time.

The guidelines recognise that individual and family circumstances change and accordingly dwellings must be able to accommodate these changing needs. Issues around sustainability, energy efficiency and smart technologies are incorporated to ensure an integrated approach to the design, construction and future proofing of a Universally Designed home. The guidelines highlight the following design qualities as essential to Universal Design homes:

> "Flexibility and ease of adaptability to meet people's changing needs over time in a cost effective way;
>
> Sustainable design to improve comfort and energy efficiency; and
>
> Smart technologies to enable ease of living independently for longer."

While it is essential that universally designed dementia friendly dwellings are accessible, usable and easily understood by all people, it is also critical that they align with sustainable design criteria. The Universal Design Guidelines for Homes in Ireland bring together Universal Design and sustainable design in a manner that is rare among much Universal Design literature. The section to follow will examine sustainable dwelling design in order to identify specific issues that

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may need closer examination in the context of a Universal Design approach for dementia friendly dwellings.

5.3 Sustainable Dwelling Design

Sustainable dwelling design is a field that is continually evolving and many of the innovative practices and technologies now being employed require a shift in thinking and behaviour on the part of dwelling occupants. Low energy heating and lighting systems or onsite micro-generation, which use wind turbines or photovoltaic panels, are making dwellings more technologically complex. Even 'passive house[1]' design, which seeks to simplify or even eliminate traditional heating systems, is dependent on mechanical heat recovery ventilation systems, which require the changing of filters to maintain internal air quality (Sustainable Energy Ireland, 2008). In terms of dementia friendly dwellings, such innovative approaches, or more complex technological solutions, may be problematic due to the many challenges living with dementia poses, as described previously in Chapter 4.

Sustainable design is also evolving to include a greater emphasis on inclusion, health and wellbeing, and security and safety. These issues also have relevance to dementia friendly dwellings and some of these, such as "universal access", covered under Universal Design, are central to this research and are thus discussed in great detail throughout this report. However, others such as noise, adaptability, and safety and security, may benefit from further exploration in the context of sustainable Universally Designed dementia friendly dwellings.

The guidance document 'Quality Housing for Sustainable Communities', published in 2007, provides in-depth detail about sustainable dwelling design (DEHLG, 2007). It sets out a number of principles and criteria which include the following;

- "Locating dwellings close to shops, schools, workplaces, and transport nodes"
- "Optimising the energy performance of the building so as to reduce CO2 emissions in the context of the general intention of substantially improving the energy efficiency of new homes by 40%"

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1. A passive house is an energy-efficient building with year-round comfort and good indoor environmental conditions without the use of active space heating or cooling systems. Source - SUSTAINABLE ENERGY IRELAND 2008. *Passive homes : guidelines for the design and construction of passive house dwellings in Ireland,* Clonakilty, County Cork, Sustainable Energy Ireland.

- "Making optimum use of renewable materials and reducing the need for the use of natural resources and non-renewable materials in the construction and future maintenance of the building"
- "Reducing the consumption of natural and scarce resources during the lifetime of the building through the use of efficient, low-maintenance systems, components and fittings"
- "The maintenance of a high quality indoor environment, e.g., through avoidance of the use of products and materials that may adversely affect indoor air quality or comfort"
- "Minimisation of waste production during the construction process and provision for recycling of both construction waste and domestic waste generated during the maintenance of the building"
- "Design for flexibility so as to facilitate future adaptation to the changing needs of the occupants and the maximisation of the building's lifespan"
- "Greater use of materials from local, sustainable sources, where available."

In relation to other sustainable design issues, this document refers to the following;
- The provision of recycling and composting facilities for the dwelling.
- The provision of "universal access" whereby features, such as ramps, level entrances, wider doors and access corridors, etc., would also facilitate ease of circulation for children and older people" (p53).
- Design for safety and security which not only refers to protection from injury, fall, fire etc, but also to issues around safety from crime, fear of crime and crime prevention through environmental design.

The position adopted in the 'Quality Housing for Sustainable Communities' guidelines represents a holistic approach to sustainable housing, similar to the Code for Sustainable Homes. The issues highlighted in this document, while not exhaustive, provide a good basis from which to select key sustainable design criteria which may need specific attention in terms of dementia friendly dwellings.

Sustainable Housing Design	Universal Design of Dementia Friendly dwellings	Notes
Dwellings close to shops, schools, workplaces, & transport nodes.	✔	This is also key for Universal Design of dementia friendly dwellings in terms of social integration and inclusion.
Optimise energy performance.	✔	
Optimise renewable materials and reduce use of natural resources in construction.	✔	
Reduce consumption of resources through efficient, low maintenance systems,	**!** - **investigate further**	Systems must take account of memory loss, cognitive impairments & fluctuating perception of temperatures.
Maintenance of a high quality indoor environment.	**!** - **investigate further**	Perception of temperature and sensitivity to noise needs careful attention.
Minimisation of waste production during the construction process	✔	
Design for flexibility so as to facilitate future adaptation to the changing needs of the occupants and the maximisation of the building's lifespan.	**!** - **investigate further**	Take account of the specific needs of people with dementia & the progressive nature of the condition.
Greater use of materials from local, sustainable sources, where available.	✔	
Provision recycling & composting facilities for the dwelling.	**!** - **investigate further .**	Careful design due to the symptoms of dementia
Provision of "universal access" (Note: Universal Design is the approach being adopted in this research).	✔	Dementia friendly dwellings requires a specific approach however this is central to all material in this report (covered elsewhere).
Design for safety and security.	**!** - **investigate further**	This needs careful consideration.
✔ = requires no further elaboration **!** = investigate further		

Figure 17 – Key Design Criteria for Sustainable Dwellings

Figure 17 lists the main design criteria for sustainable dwellings and indicates whether or not any further investigation is required in the context of Universal Design of dementia friendly dwellings. In each case a tick mark indicates that this issue is applicable to both sustainable design and the Universal Design of dementia friendly dwellings without any real modification.

An exclamation mark denotes that while the issue is relevant, there are specific concerns that need to be examined in terms of Universally Designed dementia friendly dwellings.

Where relevant an exploration of the sustainable housing criteria, as highlighted in Figure 17, will be included in each of the sections to follow. These will cover the five aspects of the Universally Designed dementia friendly dwelling, as described at the beginning of this chapter.

5.4 Home Location and approach

5.4.1   Home Location

Getting out of the house is important for everybody, including people living with dementia and their family caregivers. Moving about outside allows us benefit from fresh air, get exercise and for social interaction. Burton and Mitchell (2006) argue that simply being out on the street has positive effects that should not be underestimated. However, people living with dementia may be far more restricted than others with respect to using the outdoor environment independently. If a person can no longer drive or can no longer use public transport unaccompanied, their choice of destination is more restricted to within walking distance from home unless they can be driven or accompanied to these places. The most common destinations for people living with dementia are the shops, the post office, visiting family and friends, the GP, the park and the church. Ensuring that the person can get out and about safely and effectively in the locality for these purposes is important and will help reduce the risk of a person becoming housebound (Burton and Mitchell, 2006).

When designing new homes, the choice of location is always important and must be carefully considered. Recommendations regarding the location of residential long-stay care settings (Cantley and Wilson, 2002) are also applicable to the home care setting. Accordingly, a well-designed dwelling for people living with dementia and their families and carers will be accessible by private and public transport, whether in urban, suburban or rural areas. Locating the home in the community with easy access to shops and transport facilities will also make it easier for friends and family and formal carers to visit. Obviously it will only be possible to choose the location of the home when it is a new build or when a person is buying a new home and even then it may be necessary to compromise. Figure 18 shows the ideal location of housing for older people in relation to local services (Burton and Mitchell, 2006).

Figure 18 – Burton and Mitchell (2006) argue that ideally primary services should be within 500m of an older person's dwelling, while secondary services should be within 800m.

Box 1: Six Key Design Principles to Support Dementia Friendly Streets

Familiarity; this concept has already been discussed in Chapters 3 and 4 and has similar application in the context of the street.

Legibility; understandable sense of place and way finding achieved through the provision of good signage and multiple cues to help with way-finding and legibility. In the urban context, this means that "Legible streets have an easy to understand network of routes and junctions with simple, explicit signs and visible, unambiguous features" (Burton and Mitchell, 2006, p.64)

Distinctiveness; this relates to the "extent to which the streets give a clear image of where they are, what their uses are and where they lead" (p.78). This concept aligns with many of the issues discussed in Chapter 3 in relation to the provision of an environment that is easy to interpret, provides distinct spaces, and provides good visual access.

Accessibility; Burton and Mitchell define this as "the extent to which streets enable older people to reach, enter, use and walk around places they need to visit, regardless of any physical, sensory or mental impairment" (p.92). Accessibility is discussed at length in this report and is central to Universal Design.

Comfort; defined as "the extent to which streets enable people to visit places of their choice without physical or mental discomposure and to enjoy being out of their house" (p.104).

Safety; Burton and Mitchell define this as "the extent to which streets enable people to use, enjoy, and move around the outside environment without fear of tripping or falling, being run-over or being attacked." (p.115). Concerns about the safety of people with dementia living at home have been discussed in various sections in this report and this issue is a critical issue also in the urban context to ensure people living with dementia are not afraid to venture outside.

Appropriate home location aligns with the first design principle of the Universal Design Guidelines for Homes in Ireland (Centre for Excellence in Universal Design at the National Disability Authority, 2014). This states that dwellings should be 'Integrated into the neighbourhood'. Section 1 of the Draft Universal Design Guidelines for Homes in Ireland, 'Home Location and Approach' contains Universal Design guidance for the roads, streets and pavements that surround a Universally Designed home. The WHO (2007) has produced a

guide for the development of age-friendly cities. In the context of dementia, the design of the local neighbourhood is critical and in response to this Burton and Mitchell (2006) have presented specific recommendations for designing streets and neighbourhoods for older people, particularly those with dementia, but these are also relevant for older carers of people living with dementia. Echoing many of the dementia friendly design issues highlighted in Chapter 3, the authors propose six key design principles to support dementia friendly streets (see Box 1)

Older people have reported fears about being attacked when out in the neighbourhood and many do not go out after dark, or avoid empty places as a result (Burton and Mitchell, 2006). The neighbourhood structure is a strong predicator of fear of crime for many adults (Scarborough et al., 2010) where fear of crime can contribute to higher levels of anxiety, depression and distrust, and can negatively affect health and well-being. Scarborough et al. (2010) also point to research that identifies older people and women as those most fearful of crime.

In response to real and perceived fear of crime, a planning, urban design and architectural design approach known as 'Crime Prevention Through Environmental Design' (CPTED) has been developed in the US by Crowe (1991). This aims to promote environmental design and management practices that create safer places for inhabitants and discourage criminal activity by increasing passive security and making targets more unattractive for criminals. CPTED is also concerned with reducing fear of crime by designing out spaces that make people feel insecure or vulnerable. Various guidelines have been developed for CPTED at the urban level (Balducci et al., 2007, CEN, 2007) and in 2005 a European Technical Specification called 'Prevention of crime - Urban planning and building design – Part 3 – Dwellings' was published containing specific advice for residential dwellings (CEN, 2005). The stated objective of this guidance includes the following:

> "Most offences are committed because perpetrators enjoy opportunities: easy access, hiding places, absence of demarcation between public and private space, poor lighting and/or favourable landscaping. By understanding the motivation of potential offenders and counterbalancing it by specific physical security measures combined with real or symbolic design elements, this Technical Specification aims to assist designers, planners, estate managers and stakeholders in the area of crime prevention to: a) Define the protection

measures most appropriate to the site. b) Influence decisions relating to building design, the layout of the site, landscaping, and other related details in order to make dwellings attractive and safe for inhabitants and unattractive targets for potential offenders." (p.4)

This guidance is also about preventing access by unwanted visitors, degradation of the environment and reducing the fear of crimes "as perceptions of crime often exceed the reality." (p.4)

The CPTED document provides guidance for the public, semi-public, semi-private and private spaces around individual dwellings and apartment blocks. It also refers to lighting, the accessibility of the external envelope and intruder alarms.

While concerns around security, fear and perception of crime are applicable to the wider population, people living with dementia who may already feel insecure, anxious and fear getting lost when outside may benefit from CPTED approaches. These design approaches not only reduce realistic opportunities for criminal activity, but more importantly in the context of the Universal Design of dementia friendly dwellings, help create public, semi-public, or semi-private spaces that feel safe and secure, legible, and that are overlooked by neighbours. One of the aims of a Universal Design approach for dementia friendly dwellings is the location of dwellings which encourage social interaction with the community and create attractive semi-private and private outdoor spaces that encourage people to go spend time outside. Some of the principles of CPTED can help in creating these spaces by ensuring that these spaces feel secure and inviting.

5.4.2 Approaches to entrances

Colour and the placement of distinctive, familiar objects have both been used in residential long-stay settings to help orientate people living with dementia and to assist them locate their own bedrooms (Calkins, 2010). There is some evidence to suggest that the use of specific colour has a beneficial effect in that it helps residents to distinguish the doors to their rooms (Lawton, 1984). As far as we are aware, no studies addressing the use of bright colours to orient people living with dementia to the front door of their dwelling have been undertaken, although Croftspar, in Glasgow, a small scheme of seven supported houses for people living with dementia designed around a courtyard is viewed as a success. There the residents can

walk around the courtyard until they find their own front door, recognisable by a distinctive bright colour.

Figure 19 – Croftspar, Glasgow © Andrew Lee

5.5 Entering, exiting and moving about the home

5.5.1 Entering and exiting the home

In new buildings in Ireland, all entrances must be designed to comply with Part M of the Building Regulations, 1997-2010 and must be accessible. However, entrances to many existing dwellings are not currently accessible. Physical environmental obstacles have been identified as a fairly common safety issue in the homes of people living with dementia and their families. For example, in a US study steps to get inside the home (almost half (44%) of which had no safety railings) were identified as the most prevalent physical obstacle in the homes of people living with dementia (Marquardt et al. 2011).

Uneven lighting can create unsafe transition areas and can be hazardous for a person living with dementia. Lighting at entrances to the home is therefore an important consideration to ensure safe transition and access into the dwelling. Improved lighting in transition areas will also be of benefit to anyone accessing the dwelling including family members and carers (both informal and formal).

Buildings for Everyone: A Universal Design Approach Booklet 2 *Entrances and Horizontal Circulation,* produced by the Centre for Excellence in Universal Design at the National Disability Authority, draws attention to the sometimes conflicting functions of entrances. In this booklet, the question is asked whether the building entrance serves to let people in or keep people out. As shown in Chapter 4, the issue of keeping a person living with dementia safe and disinclined

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to leave the house is a very common concern associated with caring for a person living with dementia in an environment not designed for that person's use (Fleming, Crookes and Sum, 2009). It has been argued that in such circumstances, it may be necessary to curtail accessibility and use environmental interventions at the entrance to ensure that they are not alerted to opportunities to leave. Environmental interventions that could prevent 'exiting' or 'wandering' include painting the inside of the door the same colour as the surrounding walls, "hiding" the door or doorknob by a curtain or adding door chimes as an auditory alert that the door has been opened (Day, Carreon and Stump, 2000).

In a study conducted in a Specialist Care Unit for people living with dementia, visual barriers serving to camouflage doors or door furniture were found to be an effective and cost-efficient way of reducing residents' desires to exit through doors with window panels (Dickinson et al., 1995). In a small-scale US study Mann et al. (1996) found that house modifications were generally undertaken by family caregivers to restrict wandering and included installation of double-keyed deadlock bolts. Similarly, in a more recent study, Marquardt et al. (2011) found that most family caregivers were not aware of environmental interventions that might enhance functional ability. In the same study it was shown that when exit control became important, in the moderate stages of dementia, 39% of caregivers locked the doors or used some kind of auditory alert.

Smart technology in the form of exit risk messaging (i.e. alerting a family member or carer that the front door has been opened) can also be used in the home in an attempt to safe proof it. Using a case study approach, the Bath Institute of Medical Engineering evaluated the use of this technology in UK care homes. The aim of this technology was to provide a prompt to alert staff when the resident left the home. The intervention took place over a 12-month period. The dwelling was a sheltered housing flat with high levels of support for a woman who lived alone and who had moderate dementia. The effectiveness of the system was measured using Individual Prioritised Problem Assessment (IPPA), supplemented by semi-structured qualitative interviews with the tenant, her family and formal carers to record their views. The system was consistently assessed to be effective by the formal carers who felt that it was necessary to be called if the front door was opened during the night-time risk period. However, the tenant neither liked the noise of the call system nor the staff coming and she felt constrained by the technology, particularly with regard to her freedom to open the front door and look about (Evans et al., 2011).

Fleming, Crookes and Sum (2009) report that there is some evidence to support the use of unobtrusive safety features but they also caution against overemphasising safety features. With respect to locks on doors, Fleming et al. (2009) ask the question 'wouldn't it be better if residents could go outside and be safe?' Research in a long-stay residential setting has shown that residents with Alzheimer's disease showed a dramatic improvement in their agitation, aggression and wandering behaviour following an encounter with an open door as opposed to a locked door (Namazi and Johnson, 1992). Moreover, qualitative research has shown the value the outdoor environment for people living with dementia for a variety of reasons including exercise, fresh air, better emotional well-being, the opportunity for informal encounters with neighbours and friends and the appreciation of the countryside. Conversely, not being able to go out is associated with loss of independence, loss of control and feelings of depression (Duggan et al., 2008).

Guidelines for the Use of Disguised Doors and Other Preventive Exiting Strategies for People with Dementia developed by the Bureau of Aging and Disability Resources in the Wisconsin Department of Health and Family Services, state that 'disguised doors should never be the only intervention used to preventing a person from leaving a facility or home. Disguised doors are only one kind of deterrent and are literally at the point of exit'.

5.5.2   Moving about the home

Horizontal Circulation

Buildings for Everyone: A Universal Design Approach Booklet 2: Entrances and horizontal circulation published by The Centre for Excellence in Universal Design at the National Disability Authority (2012) states that "the overall arrangement of access routes should be logical, understandable, useable, and as direct as possible in terms of providing access to key facilities". Some people living with dementia can face difficulties in trying to locate rooms such as the toilet in the dwelling. The observation that people living with dementia have a better chance of finding something if they can see it from where they are has led to the idea of 'Total Visual Access' (Fleming et al., 2009). Direct visual access to all places and rooms thus becomes evident in designing dwellings for people living with dementia (Marquardt and Schmieg, 2009).

Opinion about the value of open plan living is divided. It has been recommended that the dementia dwelling should ideally have an open floor plan. This is obtained by reducing the number of walls, and the open character of the house further enhanced by large windows that allow people to look outside (van Hoof and Kort, 2009). A house with a well-designed building layout and with clear circulation routes which are easy to follow will, it is believed, benefit people living with dementia. There are also benefits for those caring (informal and formal carers) if the person living with dementia can negotiate their way around the house unaided. However, in an exploratory study evaluating the association between the environment and functioning at home in older people with dementia, Marquardt et al (2011b: 55) found that:

> 'residents who live in a home that features a high proportion of open spaces, such as circulation areas and interconnected rooms, and fewer enclosed rooms with a clearly legible meaning and function were more dependent on others with their basic activities of daily living, such as eating dressing and using the bathroom'.

The implications of these findings are that enclosed rooms with a clearly legible meaning and function might be better memorised and associated with the spatial layout of the home resulting in better performance of activities of daily living. Marquardt et al. (2011b) note that the results from their study warrant further research and they are pursuing a longitudinal study on this topic.

Furthermore, findings from a post-occupancy evaluation of Croftspar, the small scheme in Glasgow referred to earlier, suggest that people living with dementia do not always like open plan living.

(a)   Corridors

Studies from long-stay residential settings suggest that long featureless corridors can make people living with dementia more confused and can create restlessness (Calkins, 2010). A clear layout, with a minimum of corridors, and uninterrupted visual access to all or as many areas and entrances as possible is therefore recommended to compensate for this difficulty and enable people living with dementia to go from one space or room to the next without having to plan for future decisions. This idea has led to the development of simple, corridor free environments (Fleming et al., 2009). Drawing on this idea, van Hoof and Kort (2009) have

designed a dwelling for people living with dementia with no corridor but with an entrance that directly leads to the living room. They also made much use of sliding doors, which can be opened and shut according to residents' wishes for privacy. Different spaces are visible from as many locations as possible within the house. For example, the bathroom is visible from both the kitchen and the living room, thus ensuring that the person is constantly being reminded of the need to use the toilet. To make using the bathroom easier at night, they have also incorporated a sliding door between the bedroom and bathroom. Signage may also be used as an approach to help way-finding (See Section 3.3.4.).

(b)   Doors/internal doors

The Centre for Excellence in Universal Design at the National Disability Authority's Buildings for Everyone: A Universal Design Approach booklet 2 Entrances and horizontal circulation, recommends that 'doors opening into a room should be hung so that they open against an adjoining wall'. This can also be helpful for people living with dementia. Doors that open against the wall into various rooms give an immediate view of the room and its contents and thereby provide good clues to the room's function (Pollock, 2003). Electromagnetic hold-open devices, which enable doors to be held open in a fixed position, whilst generally used to allow unobstructed or easier and useable access through a building (CEUD, 2012), can also be used to give direct visual access to a room.

Given the importance attached to introducing colour contrast into a building, it is widely recommended that internal doors should be painted in colours that provide visual contrast with adjacent wall surfaces and with door handles so that they are easy to identify. It has been recommended that door handles, latches and locks should be recognisable as such to a person living with dementia.

A door that is not self-closing, and may therefore be left partially or fully open, may present a potential hazard or obstruction. Therefore, it has been suggested that the surface of the leading edge of any door that may potentially be dangerous should visually contrast with the main surface of the door so that its presence is more readily apparent.

Vertical circulation in the dwellings

Vertical circulation is the route or facility that enables a person to travel up or down in a building, from one level or storey to another. Within the home, the stairs typically provides the viable means of access between different levels of the house.

(a) Internal stairs

Marquardt et al. (2011) found that internal stairs that connect different floors form a major physical barrier for residents living with dementia. Based on their study findings, Marquardt et al. (2011) suggest that when considering new builds and renovations to existing buildings, architects, developers and planners should consider not only the accessibility of dwellings in their designs, but also the occupant's mobility within the home. They recommend that in homes with more than one floor, consideration should be given to having a bathroom on the ground floor (or at least the provision of all necessary fixtures), and a floor plan design that allows for the installation of a bathroom at a later point.

As Buildings for Everyone: A Universal Approach booklet 3 Vertical Circulation published by the Centre for Excellence in Universal Design at the National Disability Authority (2012) points out, safety is of paramount importance when considering vertical circulation in a building and stairs. The latter of course is the most common means of changing level in a house. Stairs can give rise to risk of serious injury following falls and stairs including their poor step design, and/or edges or nosing not clearly defined, and/or inappropriate and/or inadequate handrails for support are among the many hazards facing people living with dementia identified by Brawley (2001). The clear guidance given in the booklet mentioned above on the design and dimensions of internal stairs is therefore important. In addition to this guidance, contrasting colours between the steps of the staircase and the staircase frame and walls can help a person living with dementia to identify steps and changes in level or gradient, thereby simplifying the visual environment, which is also beneficial for older caregivers with age-related vision difficulties. Lighting is also very important on internal stairs so that they can be used safely at all times.

(b) Hazard warnings at the top and bottom of stair flight

Hazard-warning surfaces which provide visual and tactile contrast, as referred to in the Buildings for Everyone: A Universal Design Approach Booklet 3: Vertical Circulation published by the Centre for Excellence in Universal Design at the National Disability Authority (2012),

may be frightening to a person living with dementia and should be avoided. For example, a sharp contrast in flooring color can be perceived as a step or hole by the people who may be prone to panic and have perceptual problems. The latter may place the person more at risk of a fall inside the house.

(c) Handrails

Where people living with dementia or their family caregivers have mobility or visual difficulties, handrails or grab bars can support safe mobility around the dwelling. Buildings for Everyone booklet 3, provides guidance for the provision of handrails. Of particular importance is that handrails should be available in a wide range of colours for people living with dementia, and they should contrast in colour with walls. The idea is that they are clearly visible and thus enable the person living with dementia to see them (DSDC, 2010)

(d) Stairlifts

Best practice on the use of stairlifts, which are designed for domestic use only, has been provided by the Buildings for Everyone: A Universal Design Approach Booklet 3 Vertical Circulation published by the Centre for Excellence in Universal Design at the National Disability Authority (2014). However, it is recommended that much care should be taken with regard to any decisions regarding the installation and use of stair-lifts for people with dementia living in their own homes. Assessment by a trained occupational therapist is recommended.

5.6 Spaces for living

The careful design of individual rooms is important as it will impact on issues such as the extent to which retained abilities are supported or hindered as the dementia progresses. Design also has obvious implications for those providing care (informally or formally) to the person living with dementia as it may facilitate or hinder carer support. Design will also impact on the overall quality of life of both the person living with dementia and his or her caregivers. The section to follow will now report on bathrooms, kitchens, dining rooms, and bedrooms. Having only one activity or function associated with each room helps the person living with dementia to develop a familiarity with the room. For example, the smell of food being prepared in a kitchen, or the soft calm lights radiating from a bedroom, or coats and keys hanging in the hallway. Colour also helps people living with dementia to distinguish one room from another.

5.6.1   The bathroom and WC

Personal care including toileting, showering and hygiene maintenance are often central to the care relationship be that formal or informal, so the bathroom can often become one of the most important rooms in the house. Key issues here are space, access, easy identification, safety, and future proofing. Addressing these issues through Universal Design will not only benefit the person living with dementia, but can make caring easier for carers (both informal and formal).

In a US study, Marquardt et al. (2011) found that the most common modification in the homes of people living with dementia related to bathroom safety. They found that bathroom modifications such as walk-in showers, handheld showerheads or a shower seat were made in nearly 50% of all homes visited: another 57% had grab bars installed. A modified bathroom that featured at least three important safety features - grab bars, a walk-in shower and a shower seat - was found in only 23% (n=19) of homes in the sample. Marquardt et al (2011), however, found that the modifications made were of varying quality. In the National Disability Authority survey of disability conducted in 2006, the largest unmet need identified by the researchers was bathroom aids and grab bars (National Disability Authority, 2006).

Namazi and Johnson (1991) investigated the effects of making the toilet visible and found that people living with dementia are more likely to use the toilet when it is visible. This reinforces the importance of a person being able to see what is needed when it is needed. Painting bathroom or toilet doors in strong distinctive colours, which contrast with the surrounding wall and using clear signage written in words and portrayed in pictures, may also aid recognition.

Colour and contrast is particularly important within bathrooms. To reduce confusion, a variety of contrasting colours can be used. For example, the toilet seat can be in a colour that contrasts with the WC, which, in turn, contrasts with the surrounding floor and wall tiling. The sink, bath and shower area also need to be distinguishable from the surrounding floor and walls (Utton, 2009).

The existing design guidance literature suggests that to compensate for cognitive decline, sanitary ware in the bathroom should be familiar from the individual's early adulthood. Accordingly, traditional sanitary ware that may be recognised by the person living with dementia from their earlier years include traditional fittings, taps and toilet roll holders. Such

should be chosen for familiarity. For example, a cross head tap is a very traditional design and most people would instinctively know how to work it (DSDC. 2010).

Automated taps, where taps are automatically turned off if left running, have been used as part of the enabling technology in a smart flat for a person with moderate to severe dementia in the UK. Interviews with this same resident revealed that he was not aware of this enabling smart technology, but when prompted recalled experiencing it (Evans, 2007). This finding points to the unobtrusive nature of this type of technology.

 Examples of these automatic tap shut off systems such as the 'Nova-Flo' system (http://www.nova-flo.com/) also prevent unnecessary wastage of water in terms of sustainability. Such have particular relevance in the Irish context where water charges are soon to be introduced. Infra-red detectors or sensors on taps may be effective in reducing waste and minimising the need to operate taps, however such automatic controls could be very confusing for a person living with dementia. They could cause anxiety if a person went looking for the tap controls.

For some people with a more moderate to severe cognitive impairment, mirrors create confusion (as the person may not realise that the image reflected is their own) or the mirror can generate fear and cause adverse reactions. Therefore, it makes sense that mirrors in the home can be easily moved, removed completely or covered over. van Hoof et al. (2008) suggest that bathroom mirrors are heated so that moisture from the air does not condensate on them and make reflections impossible. Awareness of the potential dangers of mirrors and consultation with the person living with dementia, their family and carers would help in this regard.

5.6.2   The kitchen

Unlike some long-stay residential care settings, all domestic dwellings will have a fully functional kitchen where food preparation, cooking and sometimes eating takes place. Preparing food, eating and drinking are as much about fulfilling roles, personal pleasure and social interaction as they are about nutrition and hydration (Brush, Meehan and Calkins, 2002). Since the kitchen can often be the hearth of the home, it can also double up as a place of social activity for men and women living with dementia (Cohen and Weisman, 1991).

Davis et al. (2009) encourage us to think broadly and look at how the physical (and social) environment can support people living with dementia and give them opportunities to be involved in different aspects of the eating experience including preparing and cooking the food, setting the table and cleaning up after the meal. Keeping people living with dementia involved in cooking is a way of encouraging them to eat. Designing a kitchen to enhance nutrition, independence, self-esteem and social interaction is thus important.

Currently expert opinion states that designing for accessibility, visibility, usability and safety are of utmost importance in the design of kitchens (DSDC Stirling, 2010). This applies to all people, but is particularly important for people living with dementia and to their carers (both informal and formal). Lighting and the design of flooring are important design features. Likewise assistive technology such as cooker switch off devices and flood detectors can be particularly useful in kitchens for reducing risk and enhancing usability. It is recommended that kitchen cabinets and counters should be designed to make them accessible for people living with dementia who have physical impairments, mobility problems and sensory impairments. One suggestion offered by DSDC Stirling (2010) to compensate for memory loss is to increase visibility of food and utensils by fitting units that are open fronted or have clear safety glass. The DSDC Stirling also recommends using open shelving so that the resident can see the things that they need. Glass fronted fridges can be used to make things that people living with dementia use, including food, visible (DSDC, Stirling, 2010). The kitchen often contains recycling or brown waste bins (for composting). If these are convenient and easily accessible, both physically and visually it may help with recycling activities. (See Section 5.6.6 for external recycling and composting facilities). Overall, the kitchen requires high levels of even lighting (Brush, Meehan and Calkins, 2002), a design feature which in fact would benefit everyone living or working in the dwelling.

Cohen and Weisman (1991) suggest that in an open plan dwelling 'a sensitively designed kitchen work island or table can serve as an excellent centre for unobtrusive observation' by the carer (informal and formal). This enables the carer to keep the person living with dementia in sight while they are in the adjacent sitting or dining room. Although this suggestion is made with reference to domestic kitchens in residential long-stay settings, it has application to domestic dwellings. Designing the kitchen in this way can also encourage social interaction. Good kitchen design for all is good design for people living with dementia and their families and carers.

The kitchen is often seen as a place of risk and there are many suggestions aimed at reducing risk unobtrusively. For example, it is recommended that a standard fronted or locked cabinet can be used to protect the person living with dementia from dangerous items. Taps should have water temperature controls to prevent scalding. There is often great concern about fire and flooding and whether the person will remember to turn the cooker or taps off. Inaccessible or hidden power switches for the cooker can be another alternative to protect residents when they are unsupervised (Cohen and Weisman; 1991; DSDC Stirling, 2010). It is recommended that essential kitchen appliances should not only be selected for safety but also for usability.

Such potential risks, however, can often be reduced with assistive technology and the latter can be used both to promote independence as well as increase safety. For example, smart cookers are often suggested as a way of reducing the risk of fire. As part of the case study mentioned earlier, the Bath Institute of Medical Engineering evaluated the use of a cooker-minder system over a 12-month period with a single tenant who had moderate dementia in a sheltered housing flat with high levels of support. The evaluation found that the cooker-minder system, the aim of which was to support the independence of the resident to use the kitchen to cook a snack, was rated differently by the resident, her family and staff. Whereas staff found the system useful for alerting them to smoke from the cooker, the resident's rating of the system reduced over time. This poor rating was attributed to her gradual loss of confidence or ability in the kitchen. The family low ratings of the system were because they felt that the unfamiliar style of the cooker hindered their relative's ability to cook (Evans et al., 2011).

5.6.3   The dining room /areas

While changes can be made to the furniture, ornaments and other physical objects in the home and tasks can be simplified, structures within the physical environment can also be altered so as to enhance the eating experience. Lighting is important in the dining room/area. Research undertaken in residential long-stay care settings has found that increasing light in the dining room and lighting contrast at place settings, can positively affect eating habits among residents with dementia (E, 1998). Increased lighting, controlled glare and providing contrast can facilitate independence, improve nutritional intake and functional abilities (Brush, Meehan and Calkins, 2002). All of these features are also of course invaluable for both formal and informal carers.

5.6.4   The bedroom

Davis et al. (2009) suggest bedrooms should be designed in such a way as to make it easier to find the toilet at night and enable a person prone to moving about at night to do so safely and avoid falls. Bedroom design should be spacious with plenty of space available to move around the bed.   Good ventilation and natural lighting should be available, while artificial lighting should include both overhead and task lighting. Appropriate clothing storage and direct access to an ensuite bathroom (DSDC Stirling, 2010) should also be considered. Space within the bedroom should respond well to changes in functioning over time. As dementia progresses, wardrobes should be available with glazed doors rather than solid doors to enable visual access. Assistive technology, in the form of light sensors or pressure mats which switch on lighting automatically are also useful for controlling light at night. Such lighting, for example, can direct a person living with dementia to the ensuite toilet during the night.

5.6.5   Retreat areas for family members/carers

In van Hoof and Kort's study (2009) of the design of domestic dwellings for people living with dementia, family caregivers expressed a desire for a retreat area or room (van Hoof and Kort, 2009). This can comprise a special area in the bedroom for the carer to withdraw or carry out activities in privacy, and can be incorporated into the design of a dementia friendly dwelling. Since this was the only reference to retreat areas for family members/carers found in the literature, the issue was explored further in interviews with stakeholders including people living with dementia and their family members and carers and will be revisited in Chapter 7.

5.6.6   Outdoor spaces including gardens

As mentioned earlier, people living with dementia and their families, like any one of us, can benefit in a number of ways from outside spaces and gardens and the principles of landscape design for older people with cognitive and sensory impairment is an increasingly active field of study (Housing Lin, 2012). A fact sheet produced by the Housing Learning and Improvement Network, although targeting Extra Care or Care Home providers, has much application for those responsible for designing gardens in dwellings in which people with dementia live. Key design principles discussed in this publication such as access, movement, orientation, and using garden design to trigger positive memories including reminiscence and other sensory stimulation (using strongly scented plants), are all principles with much application for people

living with dementia in their own homes and indeed for caregivers either visiting or co-resident. Likewise creating shelter and shade, and introducing raised planters to encourage those with limited mobility to enjoy gardening activities (planting weeding, harvesting, walking, resting) reflect best practice in design[12] and will benefit older caregivers. As shown in this fact sheet, a well-designed garden can be used as part of a treatment programme. Indeed it can provide scope for physical activity to relieve boredom, tension or aggression. Landscape design should reflect changing needs and allow for activities that are familiar and encourage participation.

Outside spaces and gardens can also make it easier for people living with dementia and their families and carers to go outdoors. Gardens offer an opportunity for outdoor activities and exercise, which can be therapeutically beneficial. Many other outdoor activities besides those listed above such as lawn-mowing, raking leaves, hanging clothes on a line can also stimulate long-term memories of earlier home-life and can allow people living with dementia to be physically active and socially engaged. Exposure to natural daylight helps to regulate circadian rhythms and sleep/wake patterns (Brawley, 2001) and assists the body's manufacture of Vitamin D (Housing Lin, 2012). While the importance of improving the design of the outdoor environment for people living with dementia has been well established, the topic has received less attention than internal design of buildings for people living with dementia (Mitchell et al., 2003). Nevertheless, design suggestions for outdoor areas include the layout of footpath, suitable types of paving materials, planting, and way-finding cues such as clear navigational markers like strongly scented plants or garden features.

Pollock (2007) provides excellent general guidance. She recommends that outside spaces and gardens designed for people living with dementia should seek to provide a safe, enclosed and secure environment, with barrier-free access from the house. Gardens should have gradients of no steeper than 1:20. They should provide a level hard surfaced patio; a path leading around the garden; resting areas, views to, and over the garden, from inside the house. According to Pollock, gardens should provide limited views outside since spaces outside the garden may be an attraction for a person living with dementia and encourage exiting. For this reason the individual's attention should not be drawn to areas outside the garden.

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[12] Of course the assumption here is that most people will have a garden attached to their home.

Other elements addressed by Pollock include the patio area, path design, resting and sitting areas, garden enclosure, furnishing the garden, themed gardens, e.g. vegetable and herb gardens, trees and shrubs, choice of plants for the garden, and suitable paving. For example, she points out that fences or walls as high as 1.8 metres are usually unnecessary and a height of 1.6 metres is usually adequate for privacy. Pollock (2007) argues that in the context of dementia, the success or failure of the garden does not rest merely with the design, but is also determined by the quality of the work including the landscaping and maintenance of the garden.

Some people living with dementia and older family members and carers will have sensory impairment as, for example, poor vision. For these the garden can provide opportunities for other sensory stimulation such as touch, sound and smell. Water, for example, provided it is installed in a safe and controlled manner can generate many benefits including the tranquil and trickling cadence of a fountain. Raised garden beds will encourage people to touch plants which should be of different textures. Fruit trees will encourage birds to visit seasonally. Having a well-designed garden also means having the opportunity to keep an animal, a domestic cat or dog, which can be very beneficial to people living with dementia. The garden's seasonal changes can help with orientation by marking the passage of time (falling leaves in Autumn and snow, frost in Winter). In fact any garden provided it's carefully and creatively designed can offer a multi-sensory experience. Often the garden can have a memory awakening function which is particularly beneficial for people living with dementia (Martinez, Villez & Coupry, 2013). New models of in-home supports for people living with dementia are currently being developed in Ireland aimed at maximising quality of life for people living with dementia and their family caregivers. These involve formal carers providing individually tailored in-home supports aimed at enhancing social engagement, engaging people with dementia in meaningful activities and reinforcing their self-identity. Having a well-designed garden could support people living with dementia to maintain an interest in the garden and formal carers working within this model to achieve these goals.

External recycling and composting facilities should be provided in dedicated location convenient to the dwelling and should be visually accessible to encourage use. Again, the use of distinctive colours, or signage could help identify the area, while non-slip surfaces and containers that do not require the user to lift a bag higher than 1100mm will help with safety and usability (CEUD, 2012.p52).

The Draft Universal Design Guidelines for Homes in Ireland (CEUD, 2014) will provide guidance around the Universal Design of recycling in homes, including the communal composting faculties in apartment buildings. The Universal Design of dementia friendly dwellings is also concerned with ensuring that communal refuse or recycling facilities in apartment buildings are fully accessible, usable and understood by people living with dementia, in addition to all other users. The route to these facilities must also be easily navigated by a person living with dementia to ensure it is possible and desirable for them to use these facilities without becoming disorientated.

5.7 Interior design in the home

The interior of the house can be designed to compensate for difficulties associated with dementia and to help people living with memory and cognitive problems to remain as independent as possible (DSDC, 2010). The section to follow will review the literature on colour and colour contrast and will provide a description of the ideal materials for surfaces, floors, wall and ceilings in dwellings for people living with dementia, their families and carers.

5.7.1   Colour and contrast

There is some debate in the literature about how dementia affects perceptions of colour. Some research has indicated that the ability to discriminate between colours remains well preserved (Wijk et al., 2002), whilst other studies report that people living with Alzheimer's disease find it more difficult to distinguish between colours, especially in the blue and green areas of the colour spectrum, compared with the yellow and red areas (Wijk et al., 1999). Designing a colour scheme that minimises the use of these shades has thus been recommended (Calkin, 2002; Dunne, 2004).

As mentioned earlier in this report, several design publications (Habiteg, 2010; Utton, 2007), including those aimed specifically at designing the home environment for people living with dementia (DSDC, 2010), have emphasised the importance of introducing colour contrast. It is suggested that the use of contrast is beneficial to people with both dementia and visual difficulties. Colour contrast can also help compensate for impaired reasoning. For example, contrasting colours or the same colour through the use of sharply contrasting tones can help to distinguish between different surfaces and between surfaces and objects. Contrasting colours

can be used to distinguish doors from the surrounding walls and thus facilitate recognition of access points and make the environment easier to negotiate and understand (Torrington, 1996; Zeisel, 1999). A simple and cheap option to identify contrast levels is to take a black and white photograph of a room and see how easily the furniture stands out against its surroundings. Introducing colour contrast into the dwelling will be of benefit to all occupants.

People living with dementia can sometimes mistake one room for another. While this is often less likely to be a problem if the person lives in their own home, it becomes a greater problem if major extensions or adaptations are carried out to the person's original home. It has been suggested that way-finding can be improved if care is taken to make each room distinctive in its décor so that it is visibly different (Timlin and Rysenbry, 2010). Using particular colours for specific rooms or fittings may act as a simple cue to help with recognition. While colour-coding can be a highly individual and creative exercise, it is imperative that the information being communicated through colour is consistent throughout the home. In fact, it is said that predictability and order can be achieved in the environment through consistent repetition of colour systems (Cohen and Weisman, 1991).

5.7.2   Surface finishes

As reflections on glossy surfaces can interfere with visual perception and can cause discomfort including that arising from glare, matt finishes are recommended to reduce reflections and glare (Bakker, 2003; Torrington and Tregenza, 2007). Where glossy surfaces are used, positioning is important to avoid light sources from producing reflections close to the line of sight (Torrington and Tregenza, 2007).

5.7.3   Floor finishes

It is equally important to choose a floor covering that is not shiny and reflective due to glare and other visual difficulties. Thus, where hard floor surfaces are needed, for example, in kitchens and bathrooms, matt finishing is recommended. Matt finishes are also important since a shiny floor can be misinterpreted by a person living with dementia as representing water and being wet and slippery. The risk here is that the latter might cause the individual to alter their gait when walking over it and result in their falling (DSDC Stirling, 2010). This also applies to any person with a visual difficulty. Floor finishes can also make a difference to carers (informal and formal) who pending their circumstances (age and mobility) may be prone to falls.

Where there are problems with depth perception, a sharp contrast in flooring can be perceived as a step or hole by a person living with dementia (Calkin, 2010). A person diagnosed with dementia can walk more quickly and safely across a smooth matt surface of one colour. For this reason, best practice is to choose one colour only and use this same coloured flooring throughout the home, including in the kitchen, bathroom and living areas. Using carpet bars that are the same colour as the flooring at the threshold between two rooms is also helpful as it reduces the risk of the person thinking that it is an object in their path that they must step over (DSDC Stirling, 2010). Again, this applies to a person with vision difficulties.

Expert opinion has for many years considered that patterned carpets or dark contrasting carpet borders may increase visual-spatial difficulties and cause walking problems and falls for residents with dementia. This anecdotal evidence has now been supported by the findings from a research study, which examined different characteristics of carpet design on 107 individuals living with dementia. The researchers in this study found that larger patterns and high contrast within the pattern is associated with greater problems such as sidestepping, reaching for a handrail or veering (Perritt, McCune and McCune, 2005). Patterns on floor coverings that represent real life objects can also be problematic. Because of this, plain and similar coloured floor tones should be used. However, it is argued that if the person is in his/her own home and the patterned carpet is familiar, that person is less likely to have a problem (DSDC Stirling, 2010). It should be noted, as mentioned earlier, carpeting can hinder a formal carer attempting to assist a person with a mobility aid to move about the home.

5.7.4   Wall and ceiling finishes

Based on the idea that introducing colour contrast is important for people living with dementia (see section 5.7.1), it is recommended that skirting boards and door frames are in a contrasting colour to walls and ceilings and that a clear contrast is made between floor and wall finishes and between handrails, grab rails and the walls behind. It is also recommended that contrast is made between light-switches and the walls behind.

Bold and repetitive wall paper patterns and those with real life objects such as flowers can cause fear, restlessness, frustration, delusions and confusion. For example, trying to pick patterns such as flowers or leaves off the wall can cause much frustration. For this reason, it is

widely recommended that walls are decorated with muted or pastel colours (van Hoof and Kort, 2009). Eggshell or silk finish paint is recommended as it reduces glare.

5.8 Internal services in the Home

The next part of this chapter will consider specific aspects of the internal environment, namely lighting, heating and ventilation, and the acoustic environment. It will also look at sustainability issues within dwellings with a particular emphasis on efficient resource consumption in relation to both energy and water use. As discussed earlier, sustainable housing has become more complex in the drive towards efficiency and energy conservation, and while this is producing results, it often involves more technology, and in some cases for occupants to change their behaviour. The conservation of heat within a building, the maintenance of comfortable internal temperatures, heating, ventilation, lighting and domestic hot water controls, all have implications when designing for people living with dementia and likewise indeed for their families and carers living in and coming to work in the home. These issues, along with water conservation, which is another important sustainable design issue, will be examined in the next part of this chapter.

5.8.1   Lighting

Much reference has already been made to the salience of both natural and artificial lighting in the context of designing the dwelling appropriately for a person living with dementia, their families and carers and lighting is considered one of the most important aspects of the indoor environment for people living with dementia (van Hoof and Kort, 2009; Torrington and Tregenza, 2007). Lighting is essential for vision and is important for:

- compensating for deterioration in vision.
- providing even illumination and reducing effects of glare through good positioning and design of the lighting.
- enhancing task visibility, including with regard to recognition of places, awareness of hazards and activities of daily living.
- ameliorating sleep disturbances and reducing challenging behaviours.

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While the evidence presented below is mostly obtained from research in long-stay residential settings, the findings and guidance appear to be equally applicable to other settings including the family home. The rest of this part of the chapter will draw on a range of literature including a review by Torrington and Tregenza (2007), which summarises the evidence from the research literature and considers the implications of lighting design for people living with dementia.

Compensating for deterioration in vision:

People living with dementia need higher than normal levels of lighting to compensate for visual impairment (Brawley, 2001; Pollock, 2003; Torrington and Tregenza, 2007), which may be related both to the ageing process as well as the dementia.

Provide even illumination:

Adaptation times from dark to light or from light to dark increases with age. The lighting of rooms where dark and bright parts exist can inhibit vision. Too little light producing dim or dark surroundings and poorly lit areas and uneven light that may create shadows; uncontrolled glare and reflections, and unsafe transition areas can hinder people living with dementia and at the extreme can act as hazards (Brawley, 2001; Torrington and Tregenza, 2007). Torrington and Tregenza (2007) found the most common cause of uneven illumination in residential homes was failure to supplement partial daylight with adequate electric lighting.

The use of ceiling-mounted luminaires is recommended as a non-intrusive way of introducing high intensity light (van Hoof,). However, Torrington and Tregenza (2007) warn that very uniform illumination (e.g. from a diffusing ceiling-mounted luminaire) minimises illuminance differences between surfaces. The latter reduces clues to the form of the room and hinders orientation. Indeed, a change in lighting levels can help residents to distinguish between and recognise various spaces. Light in itself attracts people and it has been observed that cognitively impaired people are drawn to light (Torrington, 1996).

Reducing effects of glare:

Earlier on we have referred to the dangers of glare for people living with dementia. Direct light from artificial sources and natural light from windows can cause glare, which tends to become more pronounced with age. Glare can generally be divided into two types, (i) discomfort glare and (ii) disability glare. Discomfort glare results in an instinctive desire to look away from a bright light source. Disability glare makes it difficult to see an object or to carry out a task

without necessarily causing discomfort. Thus, the position of lights should be given special consideration. For example lights at eye level can cause glare and indirect sources of light are recommended. Sources of direct light within a person's field of view should be of low luminance. Windows should have a means of excluding low-elevation sunlight such as blinds, curtains or awnings.

Enhancing task visibility:

Recognising places, undertaking activities for personal enjoyment and being aware of potential hazards are tasks that people living with dementia like any of us are involved in on a day-to-day basis. While it is generally recommended that lighting levels should be uniform throughout the building, extra and directional lighting may be needed for people living with dementia. For example, van Hoof and Kort (2009) recommend putting additional light sources in closets and cupboards for increasing task visibility. Extra and directional lighting may also be needed to view any cueing system, which may include use of colour or signage. It may also be needed to accentuate stairs and handrails, so that visually impaired people who also have dementia can move with confidence. Advice on managing artificial light (general, localised and local) is given by the DSDC Stirling (2010). van Hoof and Kort (2009) recommend higher lighting levels over the counter top in kitchens and in bathrooms. This they argue will help to promote safety, and compensate for decreasing vision. Good lighting will also make a difference to families and carers of people living with dementia who may also have some sight impairment.

Ameliorating sleep disturbances and challenging behaviours:

As light plays a role in controlling important biochemical processes and balancing Circadian Rhythms, the use of lighting appears to be a promising approach in attempts at rebalancing circadian rhythms (Gauthier and Ballard, 2009). There is good evidence from research conducted in residential long-stay care settings that increasing levels of lighting (beyond that considered as normal) in the environment where people with dementia live, can improve sleep patterns and can reduce challenging behaviours (Ancoli-Israel et al., 2003; Burns et al., 2002; Campbell et al., 1988; La Garce, 2002; Satlin et al., 1992; Sloane *et al.*, 2007; Thorpe *et al.*, 2000; van Someren et al., 1993; van Someren et al., 1997).

High intensity light with a bluish light has been shown to improve Circadian Rhythms in older people with dementia living in a residential care setting; it may positively influence restless

behaviour, delay cognitive decline and decrease feelings of depression (van Hoof et al., 2008). Other studies have shown that improving lighting in the home can have wide-ranging effects including better appetite, improved health, and self-confidence, and a decrease in loneliness and falls (e.g. Joseph, 2006). Smith et al. (2004) note that, "it is important to combine the visual stimulation from healthy lighting with other sensory stimulations—aroma, sound, and touch— and synchronize all of them with the human biological clock".

Large windows allow access to natural daylight. The dwelling can be designed so as to bring natural light into the building.   This can serve to promote the well-being, of both the person living with dementia, and family members and carers. In this way, natural lighting can contribute to the creation of a therapeutic environment. In addition to being an important source of natural light, windows can be designed to provide natural or interesting views which can be used to promote quality of life. Although there has been little research on the value of a view to people living with dementia, Torrington and Tregenza (2007) draw on strong evidence that the provision of a natural view can have a measurable beneficial effect on all people. They infer that an attractive or interesting view from windows can have an equally beneficial and therapeutic effect on people living with dementia.

Other studies supporting this argument include Chalfont's works (2006). The latter conducted observations in care homes, and reported that the presence of view windows can enhance social interactions since people tend to group in seats around an attractive window and the view itself provides an easy opening for conversation. Based on their own observations in care homes, Torrington and Tregenza (2007) report that views of everyday activities of people, such as children on their way to school, are attractive to those who are confined indoors. They conclude that window positions and sill heights should be related to the probable activities of people inside, in particular whether they are walking, standing or sitting. Like other areas of the literature described in this report, while these studies have been conducted in residential long-stay settings, they also have relevance to the domestic setting. Since attractive views may encourage exiting, care must be taken as outlined in Section 5.6.6 to minimize views beyond the garden and to enclose the garden with walls or fences of adequate height.

Earlier on we discussed the use of assistive technology in the design of homes for people living with dementia. Automatic lighting is another form of smart technology that is available and can be used in home dwellings. The Bath Institute of Medical Engineering evaluated the use of

automatic lighting over a 12-month period by a person with moderate dementia in a sheltered housing flat and found that the automatic lighting system, although initially confusing for the resident, was later (after having it tailored to the resident's needs), found to be effective in allowing the resident to move safely and easily around the home. The technology was positively appraised by the resident (Evans et al., 2011).

Automatic lighting systems can also provide more energy efficient solutions by turning off lights in rooms when they are unoccupied (see stakeholder interviews in chapter 7 for further discussion of same). Automatic lighting control systems can also be employed to adjust to natural lighting conditions during the day. Brophy and Lewis (2011) outline a number of lighting controls including; occupancy sensors which only operate when someone is in the room, lighting with day lighting ballasts and light-sensitive photocells that adjust artificial light output in line with daylight conditions, photocells on outdoor lighting to adjust according to natural light levels, timing devices and dimmer switches to regulate lighting operating times and intensity levels. The Dementia Services Development Centre (DSDC) in Stirling refer to the use of movement sensors to conserve energy, but advise that settings that control the on or off timing of lights need to reflect the additional time it may take someone with dementia to move around the dwelling (DSDC Stirling, 2013). They also recommend having an option between switch operated and automatic controls as people living with dementia may not understand how automatic lighting operates and may get anxious if they look for a switch and cannot find one. It must be remembered that lighting needs to be controllable to meet individual preferences and promote a sense of autonomy (Pollock, 2003; Torrington and Tregenza, 2007).

Finally, the use of energy efficient lighting using compact fluorescent lamps (CFLs) or light emitting diodes (LEDs) will reduce overall consumption but attention must be paid to the illumination levels achieved by this lighting or the slower activation of some CFLs which results in a light coming on gradually.

5.8.2   Thermal climate and controls

People with dementia are known to be more sensitive to environmental conditions. They may, because of their perceptual problems and compared with others, have different understandings of the temperature in the home. Furthermore, a person living with dementia may not realise that the room is too hot or too cold or damp or that there is a draught coming in from under the door - they may only feel uncomfortable.

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In other words, the person may be unable to associate the room's temperature with the discomfort experienced or may not have the language skills to communicate his or her discomfort. Sometimes the person may express discomfort with the room temperature through behaviour, such as attempting to leave the room or becoming agitated, or starting to undress or alternatively endeavouring to put on inappropriate clothing (van Hoof et al., 2008).

Diminished understanding of the environmental surroundings has implications for domestic heating systems. Since people living with dementia may have difficulty judging the temperature of hot radiators or hot water pipes, it may be necessary to block or cover them to avoid the risk of burning. It is argued that electric heaters are dangerous in bathrooms and should be kept out of the bathroom (Petersen, 2002). Alternatives to radiators and electric heaters include heat lamps installed in the ceiling or under-floor heating (Bakker, 2003; Brawley, 1997), The latter has the advantage of helping to reduce incidents of falling (Mace and Rabins, 2006, Lach et al., 1995). These and other issues will be discussed below in greater detail in the context of sustainable and energy efficient space and water heating, cooling, ventilation and associated control systems.

In terms of sustainable design, energy efficient maintenance of comfortable internal temperatures is critical. In this respect, space heating, cooling and ventilation are interdependent, especially in energy efficient or passive house design. Therefore they will be considered together in the next section of this chapter.

As stated earlier, people living with dementia may perceive their thermal environment differently to others who share their space. This can result in conflicting thermal needs within the space. Having a thermal perception that differs from other people is not necessarily unique to people living with dementia. Brophy and Lewis (2011) point out that while it is common practice to design to internationally accepted fixed design temperatures, people do not passively relate to their thermal environment, and they will seek shade, shelter or sunshine, or simply change their activity or clothing to feel comfortable. Nicol and Humphreys propose taking an 'adaptive approach' that gives "occupants the chance to adjust the conditions to suit themselves. Discomfort is increased if control is not provided, or if the controls are ineffective, inappropriate or unusable." (2002. p571).

The relationship between the thermal comfort of people living with dementia and energy efficiency is a complex one that needs further investigation. Such is beyond the scope of this research. Notwithstanding this, the following section will examine some issues around providing energy efficient space heating and ventilation which are sensitive to the needs of people living with dementia and those living with them and could also benefit carers and others visiting and entering the home.

(a) **Maintain even temperatures within the dwelling** – A sense of comfort can be provided to the occupants of a dwelling by minimising temperature differences between rooms within the dwelling. Thermal mass can reduce temperature fluctuations, while appropriate window sizing and orientation, or solar shading devices can be used to achieve a more even temperature and help reduce excessive solar gain during the summer (van Hoof and Kort, 2009). Steinfeld proposes that these passive design features not only reduce the need for active heating and reduce temperature swings, but also reduce the need for intervention on the part of the occupant in order to maintain comfortable conditions (Steinfeld, 2002). Care should be taken, however, with automated blinds or other solar shading devices as these may be perceived as threatening to people living with dementia (Sweep 1998, cited in van Hoof et al., 2010a).

(b) **Under-floor heating** – The benefits of under-floor heating in terms of safety were outlined earlier. From an energy point of view under-floor heating requires lower water temperatures than radiators to attain the same room temperature and are considered an energy efficient technology because of the improved efficiency of condensing boilers and suitability for heat-pumps (SEAI, 2012; Olsen, 2002). Under-floor heating has several other benefits. It can provide a more even and stable temperature throughout the house and therefore improved comfort conditions (Waterfield, 2006). Because it radiates heat into a room, unlike convention systems like radiators or fan assisted heating panels, under-floor heating warms objects within the room, including people (Sattari and Farhanieh, 2006). Under- floor heating provides a uniform temperature from floor to ceiling; it minimises air movement which can be perceived as a draft. Olesen (2002), allows for an efficient use of space, is quiet, and requires no cleaning. By achieving the same thermal comfort with lower air temperatures, under-floor heating has the advantages of maintaining a slightly higher relative humidity in winter thereby reducing the risk of condensation and associated mould growth (Olsen, 2002). It has been found that people perceive air quality to be better

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at lower air temperatures and that radiant heating reduces conditions for dust mites. In addition, unlike convection radiators or other convection systems, the transport of dust around a room is minimised.

In summary, under-floor heating is a an energy efficient, quiet, draft free, unobtrusive, maintenance free, heating system that creates healthier, more comfortable and stable internal temperatures and therefore its installation in dwellings may be of benefit to people living with dementia and their family members/carers.

(c) **Cooling –** As discussed earlier, the avoidance of overheating, or excessive temperature differences is an important part of the Universal Design of dementia friendly dwellings and can be achieved with thermal mass, window sizes and other architectural design approaches. van Hoof refers to the use of air-conditioning for creating the right sleeping conditions (van Hoof and Kort, 2009) but warns against heating, ventilation and air conditioning (HVAC) units that produce noise or drafts. HVAC systems, which are typically electrically powered will also consume energy and with predicted hotter summers likely due to climate change (Hesterman, 2011), this consumption may increase.

Another approach to cooling that may be far less intrusive is that of radiant floor cooling. Under-floor heating systems have already been described above and one of the advantages of this system is that the same slab embedded piping system can also be used for slab and room cooling. Unlike other forms of cooling, radiant floor cooling requires no ceiling or wall mounted units, is maintenance free and requires no cleaning. Similar to radiant floor heating, radiant slab cooling provides a stable internal environment, where according to Tian et al (2008), it reduces thermal discomfort by minimising vertical temperature differences and reduces drafts.

(d) **Ventilation –** Ventilation is used for both cooling and for maintaining a healthy indoor climate. It introduces fresh air and removes pollutants and moisture. Natural ventilation provided by stack ventilation, or cross ventilation achieved by vents or openable windows (located at opposite sides of the building), can be used to ventilate and cool. For people living with dementia strong drafts can be a problem if they cause discomfort or if the draft is strong enough to cause curtains, or other interior furnishings to move. The latter can have a very disorientating effect. Mechanical ventilation is important in all bathrooms, and

can be of great benefit to people living with dementia and their families and caregivers as research has shown that a steam filled room can be stressful for people living with dementia (van Hoof et al., 2010b). However, caution is needed in relation to the use of noisy fans for ventilation as this too can cause distress. Fans that are linked to lighting so that they come on automatically when the light is switched on can be confusing for the person living with dementia who may not be able to understand what caused the fan to come on.

Mechanical ventilation, which can also be provided in en-suite bathrooms, utility areas and kitchens, can be linked to a mechanical heat recovery ventilation system (MHRV), which is an integral part of passive design dwellings. The MHRV takes exhaust hot air from these wet rooms and extracts heat using a heat exchanger to warm incoming fresh air. This reduces the heating load and eliminates the need for wall vents, which in turn reduces the heat loss through these open vents. However, MHRV systems typically require air supply vents in all habitable rooms and it has been reported by some that the air supply can cause drafts or be noisy, especially at night. Like most aspects of the dwelling, this would have to be carefully considered in the context of the Universal Design of dementia friendly dwellings due to acoustic and environmental sensitivity, and impact on sleep patterns.

(d) **Passive house design** – Passive house design approach may have some benefits for people living with dementia. Beyond the energy efficiency of a dwelling which meets the passive house standard[13], passive homes are highly airtight and typically result in a uniform and a stable thermal environment without the need for a traditional heating system. As referred to above, Steinfeld points out that passive design features also require less intervention on the part of the occupant in order to maintain comfortable conditions (2002). The stable thermal environment created in a passive house has many of the comfort and health advantages of under-floor heating as described above. The use of MHRV systems, if managed properly, can produce a high quality internal environment with reduced condensation or pollutants. The high performance envelope required will usually demand triple glazed windows and highly insulated exterior walls and roofs. The latter not only minimise heat loss, but also reduces the infiltration of external noise (Sustainable Energy Ireland, 2008). Since passive homes are not 'traditional' in many regards, they may pose an issue in terms of familiarity for people living with dementia. Passive houses are designed to

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[13] A house that meets passive standards in Ireland would achieve an A2 Building Energy Rating (BER) and highly demanding maximum space heating limit of 15kWh/(m2year) delivered energy.

remain at relatively constant temperatures throughout the day and year, and this may cause some issues for a person with fluctuating thermal comfort needs.

(e) Controls: Space heating, cooling, hot water and ventilation – While thermostats are required for controlling heating and hot water temperature, they can be troublesome for some people living with dementia. van Hoof et al. (2008) give the example of a person who attempts to control the temperature by changing the thermostat without realizing that it takes time to heat up the room. The person because of the dementia later forgets that they have changed the thermostat and thinks that the heating system is malfunctioning. One solution is to disguise thermostat controls by covering them or placing them out of sight. Another is to introduce thermostat systems that require far less intervention on the part of the resident and only functions within optimal thermal comfort range (van Hoof et al., 2008; van Hoof et al., 2010). Temperature sensors can be installed to monitor extreme temperatures and unusual changes in temperature and smart technology can be integrated into the home so that heating and room temperature controls are automatic.

Basic control systems typically have a 7-day programmable timer which controls zoned space heating and domestic hot water. This allows the user to specify heating time periods and desired temperatures. There may be several separate control panels for each function. In addition, individual room thermostats allow the user to set the desired temperature for each room. More advanced control systems will sometimes combine several functions in a centralised control panel, and link these to an external weather compensator, which all form part of a building management system (BMS). All these controls play a part in the energy efficiency of a home and with a push for increased efficiency (DECLG, 2011), and the introduction of smarter BMS, dwellings will become more sophisticated.

It is important that both basic and more advanced systems and controls are designed in line with a Universal Design approach with particular emphasis on 'Simple and Intuitive Use', 'Perceptible Information' and Tolerance for error'. van Hoof argues that people living with dementia can find a room thermostat difficult to use. The latter can also be a source of frustration to the person (2010b). It can also be frustrating for formal carers coming into the home, if systems and controls that they are unfamiliar with are not designed in a simple and intuitive way. Steinfeld (2002) reported on the difficulties experienced by his own father who found combined room controls (operating both heating and air

conditioning) confusing and hard to use. His inability to control the settings had behavioural consequences. Steinfield suggests that separate controls may help and that the control should be programmed to work only with an optimum range. This is a clear example of where the principle of 'Tolerance for error' comes into play and reinforces the argument put forward by Maki et al (2009) that products for people living with dementia should be reliable, work immediately, and that the possibilities for error should be minimised. Products should be consistent with user expectations. Information should be arranged in order of importance, minimal learning should be required and products as best as possible should be familiar and remind the user of pervious experiences.

In line with this, heating controls should be as simple and as familiar as possible and the consequences for misuse should be minimized. To comply with Part L - Conservation of Fuel and Energy - Dwellings - of current building regulations (DECLG, 2011), a certain level of space and water heating controls such as room thermostats or thermostatic radiator valves must be in place. Depending on the size of the house, separate heating zones may also be required and this will allow for greater control of heating in different rooms i.e. higher settings for bathrooms or living rooms and lower settings for kitchens or bedrooms. Cylinder immersions should be fitted with time and temperature controls so that even if somebody forgets to turn it off, it will shut down spontaneously once a certain water temperature is reached. 'Boiler interlock' systems must also be in place which automatically shuts a boiler off, regardless of time setting, if no more heat is required in the rooms or the hot water cylinder. The optimum design solution should enable the person living with dementia to have some control over their environment, but that these controls are forgiving enough not to have a significant impact on the internal environment if they are accidently misused.

Given the wide range of impairments and the progressive nature of dementia, it may sometimes be necessary to ensure that the occupant living with dementia cannot interfere with certain controls. As stated earlier, putting items including the controls in a location where they are not visible or accessible, or providing a cover over the control may be one solution. However, removing the opportunity for a person can cause undue stress or frustration. It has been suggested that for some, the provision of mock or disconnected controls, may allow a person to think that they are adjusting the room temperature, while

the real controls are out of sight. However, ethical issues around autonomy and dignity
need to be carefully considered in these situations.

5.8.3   Outlets, switches and controls

Attaching prints of light bulbs to all electric switches in the home can be useful for explaining to
a person with mild to moderate dementia the function of the switches (van Hoof, 2008).

5.8.4   Acoustics

In an earlier part of this report we have referred to the fact that people living with dementia
often have other age related sensory impairments including hearing difficulties. In cases where
their carers are spouses and older the latter are also likely to have similar age-related sensory
impairments. As mentioned earlier, noise can be very stressful to people living with dementia
(Bakker, 2003). Indeed noise is one element of the environment that requires attention when
designing and/or retrofitting dwellings for people living with dementia. The basic principle in
changing the acoustic environment is to increase sound and reduce noise, so as to help the
person living with dementia to hear important things (DSDC, 2010). As an example, soft
furnishing and carpets can be used to reduce the clattering from movement of feet or furniture.
However, consideration should be given to the type of underlay, pile height, and density to
ensure the surface is sufficiently firm as outlined in Buildings for Everyone: A Universal Design
Approach booklet– Internal Services and environment published by the Centre for Excellence
in Universal Design at the National Disability Authority. Outside noise may be welcome or
unwelcome depending on its volume. Windows are an important source of interesting
appealing sounds or annoying noise. Hence it is important that people living with dementia are
able to open or close windows (DSDC, 2010)

This issue of external noise needs to be carefully treated in higher density dwellings or those
close to sources of external environmental noise such as roads or railway lines. It has been
already mentioned that high levels of thermal insulation to homes will offer greater acoustic
protection to the occupants. The 'Code for sustainable homes', as discussed earlier in this
chapter, considers sound insulation as part of the health and well-being category and awards
points for levels of sound insulation in separating walls, floors or staircases between dwellings
that surpass Part E (Resistance to Sound) 2004 of the building regulations in England and Wales.
A maximum of four points is awarded when the airborne sound insulation values are 8dB

higher and the impact sound insulation are 8dB lower than the regulations (min 45dB for new build walls and floors/max 62dB for impact sound insulation).

The current Part E (Sound) of the building regulations in Ireland stipulates individual sound transmissions values for airborne sound as follows; walls as a minimum individual value of 49dB, floors as a minimum individual of 48dB, and impact sound as a maximum individual value of 65dB (DECLG, 2005). Therefore, while the English and Welsh regulations are already more demanding than the Irish regulations, a standard equivalent to maximum 'Code for sustainable homes' points would require airborne sound insulation values for walls and floors to be increased by 11dB, and impact values for floors also to be reduced by 11dB. The Draft Universal Design Guidelines for Homes in Ireland (CEUD, 2012) goes further than the current Irish Part E, which is to be welcome given Judd's statement that "noise is to people with dementia what stairs are to people in wheelchairs." The importance of acoustic control in the Universal Design of dementia friendly dwellings needs to be emphasised.

5.8.5   Signage and information

When considering way-finding, signage, according to van Hoof (2009: 74), 'is a logical starting point'. As mentioned earlier, due to perceptual problems, people living with dementia may have difficulty distinguishing one room from another or identifying appliances and equipment within rooms. Signage has been shown to increase room finding by people living with dementia (Nolan, Matthews and Harrison, 2001). A simple and low-cost approach to remind the person what the room is and what its function is, is to attach large clear print signs labeling the function of the room and displaying pictures or photographs at eye level at the entrance to each room. Examples include a label and picture of a toilet outside the bathroom or keys beside the front door. The DSDC Stirling (2010: 30) recommends that the base of signs should be placed no higher than 4 feet/122cm from the floor. This is supported by research undertaken by Passini et al. (2000). In a US study, the use of signs and labels was the most common modification used in domestic dwellings where it was found that only about one third (35%) had attempted to adapt their homes for their relatives with dementia (Marquardt et al., 2011).

5.8.6 Safety features

The currently available evidence strongly supports the use of unobtrusive safety features (Fleming et al., 2009) and these are discussed where relevant in all of the subsections.

In their design of a dementia friendly house (see Case study 1 in Chapter 6), van Hoof and Kort (2009) included a closet wall. This was undertaken for safety reasons and used for storing dangerous items. It also contained the home's heating system, ventilation systems and meter cupboard. The closet could also be used to safely store other potentially dangerous materials such as medication or sharp kitchen items such as carving knives or scissors. Based on discussions with family carers, van Hoof and Kort (2009) suggest that only those parts of the closet which might pose an immediate danger to the person living with dementia, should be locked so as not to undermine the individual's autonomy. Pollock (2003) recommends using plain blank doors where stored items need to be concealed to make them less noticeable to the person living with dementia.

5.8.7 Assistive technology

As noted by Cullen and his colleagues (Cullen et al, 2012), the field of assistive technology broadly speaking, refers to the practical interventions available to support the functional needs of people experiencing age-related or disability-related difficulties. Assistive technology in their view encompasses both low tech and high tech technologies. They argue that assistive technology can be cost effective as when successful, it results in a reduced demand for more expensive interventions. We would contend that in the context of dementia care, assistive technology when used carefully and ethically has the potential to significantly reduce the need for long-term residential care. However in our view, it has not to date been put to optimum use in dementia care, particularly care in the home.

Assistive technology is different conceptually from ambient assisted living, a term first coined by the European Framework Programme for research funding, its goals being to "enhance the quality of life of older people through the use of information and communication technologies". It is interesting to note that in the Ambient Assistive Living recent report (Neopil, Schauber & Glende, 2013), although reference is made to people with dementia (as "patients") and the need for more interventions to be developed to support them, there is a distinct absence of detailed information provided in this report on what type of (AAL) technologies would most

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benefit. In fact in the context of dementia, the authors refer to only practical interventions such as visible calendars and clocks to enhance temporal orientation and coding door and using room colours and photographs to enhance spatial orientation. No reference is made in this same report and in the context of dementia care to non-invasive sensors or motion detectors or telemedicine for people living with dementia.

Other useful definitions of assistive technology (AT) include that provided in the now dated Royal Commission on Long term Care (Royal Commission on Long Term Care, 1999). Here AT is defined as "any device or system that allows an individual to perform a task that they would otherwise be unable to do, or increases the ease and safety with which the task can be performed". Advances in technology have generated new devices to help support people with disabilities including those with cognitive impairments. In this context, integrating AT into ordinary homes to support people living with dementia is acquiring increasing significance. The National Dementia Strategy in England recognises that technology may play an important role in helping people to stay in their homes for longer (Department of Health, 2009). While AT can comprise a variety of features ranging from something as simple as grab rails to more advanced technology, it is this technological aspect such as *Telecare* and *smart technology* which form two main categories of AT.[14]

Telecare refers to the continuous, automatic and remote monitoring of real time emergencies and lifestyle changes over time in order to manage the risks associated with independent living. Examples include pendant alarms, fall monitors, bed motion or bed occupancy sensors, door entry/exit sensors. Other examples include sensors to record usual behaviour patterns and identify when deviations from the norm occur, and environmental hazard detectors. The latter include flood detector sensors to sense bath, sink or washing machine overflows, temperature sensors to monitor extreme temperatures and unusual changes in temperature, natural gas detectors and smoke detectors. The Alzheimer Society of Ireland has over recent years been very active through its Telecare project[15] and has installed 70 packages of Telecare equipment in the homes of people living with dementia (Connolly, 2011). Core packages installed include flood detectors, property exist sensors, smoke detectors, temperature sensors, and pendant alarms. Extra options include bogus caller panic buttons, carbon monoxide detectors, fall and

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[14] There is also a third type of assistive technology, Telehealth, which refers to the electronic exchange of personal health data from a person at home to medical staff at a hospital or similar site to assist in diagnosis and monitoring.
[15] These packages are part of the Independent European Project on Assistive Technology

gas detectors. These packages, however, are not evenly distributed across the country and at the moment have only been installed in homes in Dublin, Kildare, Wicklow, Limerick and Clare. The assistive technologies have been very positively evaluated by family caregivers. The Society has recently received €9 million from the National Lottery and intends providing an additional 13 Telecare packages in homes in North Dublin (Barrett, PC, 2014).

In an excellent critical review of assistive technology based on Ireland's participation in a seven country European study, Cullen has recently argued that assistive technology in Ireland is hugely under-developed, not well resourced and needs to be given priority from a policy perspective (Cullen et al., 2012). In this same paper, Cullen describes the different types of technologies (mobility aids, visual and hearing aids, home adaptation aids and communication aids) now available to support people with a physical disability. Although in this paper, Cullen does not specifically refer to people living with dementia, many of the technologies he describes have much application for them and for their family members and carers living in their own homes in Ireland. Cullen argues that the current reality of the public/private mix in the supply of assistive technology in Ireland is unsatisfactory compared with other countries. He contends that many different service providers, statutory and voluntary, are involved in this whole area. In his view there is a need for better organization and coordination of Health Service Executive and non-governmental organisations efforts. There is a need for guidelines on eligibility for assistive technology for training and for the follow up and monitoring of those who have had technologies installed.

Smart home technologies are comprehensive systems that combine monitoring and automation and can be tailored to meet individual need. Examples of the types of devices that are available and that are being used by people living with dementia include automatic lighting, automatic heating and room temperature controls, and automatic taps.

Using technology to assist people caring for a relative living with dementia was first showcased by the Gloucester Smart House (Chapman, 2001). This work was further developed by the European ENABLE Project, which focused on the evaluation of various stand-alone prototypes of assistive technology including item locators, automatic bedroom lamps, medicine carousels and gas cooker monitor. Based on this five country cross national study, Hagen et al., (2005) concluded that there was potential for people with dementia to utilise technology to help them

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live more independently and promote their quality of life. The idea of promoting independence in everyday life has progressed with the development of smart technology systems, and has been trialled as two long-term case studies in smart flats in sheltered housing schemes, and show potential to support independent living (Evans et al., 2007; 2011). Case study evaluation of these technologies including exit risk messaging, (such as voice reminder software alerting the individual to the fact that it may be unwise to leave the house alone at a particular time) automatic lighting, and automatic temperature controls, automated taps, out of bed messaging (to encourage the resident to stay in bed through the early hours of the morning) and a cooker-minder system have been discussed throughout this chapter. The INDEPENDENT project, a joint initiative between the Alzheimer Society of Ireland and Emergency Response, funded under an EU co-ordinated e-care programme, focuses on Telecare for people with dementia living in their own homes.

5.9 Flexibility and adaptability

As discussed in Section 3.3.4, the 'Draft Universal Design Guidelines for Homes in Ireland' (CEUD, 2014) stresses flexibility and adaptability as a key Universal Design criteria which provides "Flexibility and ease of adaptability to meet people's changing needs over time in a cost effective way" (p.7). These guidelines also recommend a number of features in bathrooms to optimise adaptability including; floor drains to allow the room be operated as a wet room, positioning the bathroom directly opposite the bedroom for direct access if required, tanking all walls in the bathroom to allow flexibility in terms of shower location, and the provision of load bearing surfaces throughout the bathroom to allow fixing of handrails wherever they are required.

A dwelling that has built-in flexibility and adaptability features will ultimately result in less disruption for the occupant which is critical for the Universal Design of dementia friendly dwellings. The design of the dwelling should minimise the need for major changes to allow a person remain at home during any modifications. The latter would eliminate the anxiety often provoked by a temporary move and alleviate the stress associated with major changes to a familiar environment. During the stakeholder engagement process, the issue of whether a person living with dementia should remain at home during home adaptation work or whether that person should be taken into temporary lodgings was discussed and will be reported on in Chapter 7. Dementia is a progressive condition and effects people in very different ways so

providing adaptable and flexible solutions is critical. Marshall believes that while design and technology can help people living with dementia, "the key to any assistance has to be adaptability. Design and technology have to adapt to meet the hugely varied needs of individuals and their families and friends" (2009.p7).

5.10. Specific design considerations for existing dwellings

So far this chapter has reviewed a range of different design approaches specifically targeting the complex needs of people living with dementia, their families and carers. The final part of this chapter will now progress to briefly address some relevant issues associated with existing homes in Ireland. This will help prioritise the key elements that may need to be addressed to align with a Universal Design approach for dementia friendly dwellings. When speaking of existing dwellings in Ireland and in order to place the discussion in context, it may be useful to provide an outline profile of this housing stock.

According to 2011 census data (Central Statistics Office, 2013) there are 1,649,408 permanent private households in Ireland. Nearly 700,000 (42%) of these are detached houses, over 450,000 (27%) are semi-detached dwellings, over 280,000 (17%) are terraced houses; and over 170,000 (10.3%) are apartments (see Figure 20). In addition, 64% of these dwellings are in rural locations while 36% are in urban locations.

Dwelling Types in Ireland

- Detached 42%
- Semi-detached 27%
- Terraced 17%
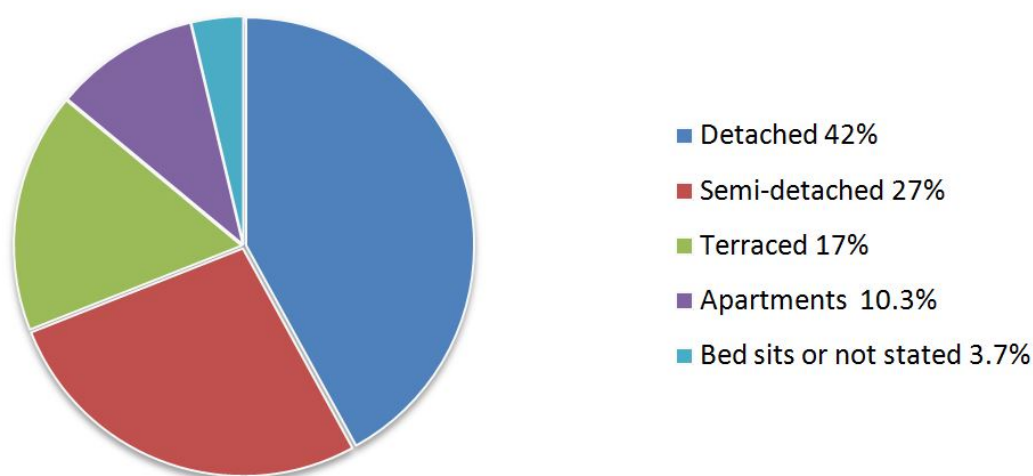- Apartments 10.3%
- Bed sits or not stated 3.7%

Figure 20 - Dwelling Types in Ireland

As already discussed in Chapter 1 (see Section 1.4), about one-third (33%) of this housing stock is over 40 years old whilst almost half of all older people are living in homes built prior to 1960. Considering that building regulations were not introduced into Ireland until 1990, many of these older dwellings will therefore not comply with current standards regarding energy use, ventilation, fire safety, hygiene, access other critical building criteria.

In terms of energy efficiency the most common Building Energy Rating (BER) for dwellings constructed prior to 1960 is a 'G' rating, which is the least efficient on the energy rating scale ('A' being the most energy efficient) (SEAI, 2013). Moreover, it has been found that over 5% of people over 60 years of age live in dwellings without any central heating. Further to this nearly 50% of people in this age group live in dwellings with oil fired central heating systems, which will become more expensive to run in light of carbon taxes and a diminishing global crude oil supply.

Based on this profile and looking back at the key dementia friendly design issues outlined earlier, the next section will examine some typical problematic building features that may be associated with these existing dwellings. Reviewing these features will determine the key aspects may need to be adapted in line with a Universal Design approach for dementia friendly dwellings.

While this report argues that all design issues should be considered in both new build and retrofit scenarios as part of the design process, it is acknowledged that in many cases certain design approaches and features may not be achievable in existing dwellings due to site and building conditions, or budget and time constraints. In these situations it will be important to select the most efficient and cost effective measures in order to carefully target time and resources invested for maximum results. The following sections outline some of the main concerns surrounding existing homes in Ireland in the context of dementia friendly dwellings. While far from exhaustive it presents a few key issues that need to be considered in this research.

5.10.1.   Location

If a dwelling is being adapted to cater for an existing occupant then the location is obviously not an issue. If however a person is planning to purchase an existing dwelling and wants to future proof this dwelling, or a local authority, or other housing provider plans to retrofit existing dwellings as dementia friendly for future residents, then the choice of location is critical. However, with 64% of Irish dwellings in rural locations it is important to consider proximity to local services, transport facilities and access for formal and informal carers as part of any long term strategy.

5.10.2.   Entering, exiting and moving about the home

As referred to earlier, Part M of the Irish Building Regulations 'Access for People with Disabilities' first appeared in 2000 (DECLG, 2000) and was replaced in 2010 by the amended Part M 'Access and Use' (DECLG, 2010). However as pointed out earlier, a large percentage of Irish housing stock has been constructed prior to this period and therefore will not contain many of the accessibility features associated with more recent housing. In terms of features for dementia friendly dwellings, stepped entrances to many older dwellings is a major issue. It must also be pointed out that while Part M 2010 stipulates a 'level access' (i.e. no steps) for the main entrance to a dwelling, it does not cover other entry or exit points such as backdoors or patio doors. As discussed earlier any step at these thresholds may pose a trip hazard to a person living with dementia and may discourage that person from using outdoor spaces or carrying out activities of daily living.

As detailed previously, internal stairs often present a major challenge to people living with dementia. Given that many Irish dwellings do not comply with Part M due to their construction date, stairs may be present which may pose problems due to excessive stair pitch, inadequate step dimensions, or lack of appropriate handrails. While the current Part M details minimum standards for stair width, step design, and continuous handrails in dwellings, it does not set out any requirements that might aid people living with dementia or their carers negotiate stairways such as colour contrast or contrasting material on steps to cater for visual difficulties.

Beyond the challenges presented by level changes, there may also be concerns around adequate circulation space within certain dwellings. For instance the original Part M 2000 directed that corridors within dwellings should be a minimum of 900mm. Where permanent fixed objects such as radiators projected into the corridor, an unobstructed width of 750mm was stipulated.

Considering that the Draft Universal Design Guidelines for Homes in Ireland calls for a corridor width between 1050 and 1200mm, while suggesting an optimum width of 1200 to 1500mm, the circulation space of 900mm (or 750mm in some places) provided in many existing dwellings may be restrictive.

5.10.3.   Spaces for living

Adequate space within a dwelling is a key component of Universal Design and this is reinforced by principle seven, 'Size and Space for Approach and Use'. While research shows that many people in Ireland consider the size of their accommodation to be adequate for their needs (Watson and Willams, 2003) there are certain spaces within typical existing dwellings that may not be large enough to facilitate wheelchairs or other assistive devices such as bath hoists. The absence of such space will also have profound effect on caregivers both informal and formal in terms of hindering how they perform certain care tasks, for example showering or bathing a person in a small bathroom can be very difficult for carers (Twigg, 2000).

Prior to Part M 2000 there was no requirement for dwellings to have a visitable WC on the entry level (usually ground floor) and therefore many existing two-storey Irish houses typically have the sanitary facilities on the first floor adjacent to the bedrooms. During daytime, when a person may spend much of their day on the ground floor, in the kitchen or living room area, having to negotiate a stairs every time they want to use the bathroom may make them less inclined to use the bathroom and more at risk of wetting or soiling themselves.   Conversely, many older two-storey Irish dwellings only have sanitary facilities on the ground floor. This is often experienced in older dwellings which would have started out with an outdoor toilet and when modernised had a ground floor bathroom built onto the rear of the dwelling. Not having a bathroom adjacent to the bedrooms on the first floor causes many issues, particularly for older people, or people living with dementia, who are forced to go downstairs at night to use the WC. This situation is compounded in dwellings with inadequate stairs, poor artificial lighting, or a lack of visual contrast on the steps.

It should also be noted that compliance with Part M (2000 and 2010) requires only a visitable WC on the entry level and does not stipulate other domestic bathroom facilities such as showers or baths. Therefore an existing house or indeed a proposed dwelling that aligns with Part M would not automatically provide a fully accessible bathroom.

Typical existing dwellings may not include direct access to garden spaces, such as patio doors (as opposed to traditional backdoors) and this may not help encourage people living with dementia to use outdoor spaces. This may be compounded if the window sill heights are set at 900mm above floor level as is often the case in dwellings constructed in the post war period. A window sill set at this height does not facilitate direct views to the exterior when a person is seated and therefore will have a negative impact on visual access to the outside. The latter may also adversely affect temporal orientation as the person living with dementia will be provided with no visual reminder from within, of seasonal change.

5.10.4. Interior design in the home

Most interior design features such as existing floor and wall finishes, or furniture and fittings such as curtains or blinds can be easily changed and therefore do not represent a significant issue in terms of making a dwelling dementia friendly.

5.10.5. Internal services in the Home

While the importance of good quality artificial lighting, safety features and Ambient Assistive Living have been highlighted earlier as key components of Universal Design and dementia friendly dwellings, many of these items can be retrofitted quite easily. One area that may require more significant adaptations concerns the thermal environment of a dwelling. As mentioned above the majority of dwellings built before 1960 perform poorly in terms of energy efficiency. As discussed previously in Section 1.4 such dwellings often result in poor health outcomes and are more expensive to heat. According to Watson and Williams (2003), in 2001-2002 only 37% of Irish dwellings built before 1940 had wall insulation, and only 51% had double glazing. Moreover, at the time of their research, almost half of people over 65 years of age lived in dwellings without insulated walls. As detailed in Section 5.8.2 the thermal climate and the maintenance of consistent internal temperatures is an important design concern for people living with dementia and this aspect of existing dwellings, especially those frequently occupied by older people, requires careful consideration.

The previous sections have identified some key elements of existing dwellings that may cause particular concern for Universally Designed dementia friendly dwellings. At the beginning of this section it was pointed out that due to site conditions or budgetary constraints associated with many retrofit projects, only certain design measures may be feasible. Echoing this approach the recent guidelines on 'Improving the design of housing to assist people with dementia' by

DSDC (2013) provides a list of top ten housing adaptations. Further to this where budgets are low, it outlines four areas that should be prioritised to provide at least for basic needs (See Box 2 below). These housing adaptations and priority areas provide a useful overview of the key dementia issues associated with existing dwellings, and reinforce much of the material previously reviewed.

Box 2: Top 10 Housing Adaptations and Four Priority Areas

Top 10 Housing Adaptations

1. Double the usual levels of lighting in the home.

2. Pay attention to acoustics and reduce noise pollution.

3. Ensure there is good signage mounted low enough for older people.

4. Use contrast of tone (rather than colour) to differentiate between walls, skirting boards and floors. Ensure that the tone of flooring/paving is consistent throughout the house and also in outside areas.

5. Use contrast of colour or tone to make switches and objects easily visible.

6. Use objects or pictures rather than colours to differentiate between rooms and different parts of the building.

7. Ensure that kitchens and bathrooms are easy to understand. Avoid modern fixtures and fittings such as taps or kettles.

8. Ensure that people can see important rooms such as the toilet, as easily as possible, and that furniture and fittings clearly indicate the purpose of each room. Use unambiguous signage on the doors of rooms.

9. Place illuminated clocks in each room indicating whether it is a.m. or p.m.

10. All doors should ideally be visible on entering the dwelling. Cupboards should be glass-fronted or open.

5.11.Construction Costs associated with Universal Design for Dementia Friendly Dwellings

As outlined in the previous section, the approach adopted in this research does not draw a sharp distinction between design issues pertaining to retro-fit and new build, as it is believed that the various design measures addressed in this research are applicable to both. It is also acknowledged that the design measures proposed vary from minor low cost items to major spatial design measures, and that the latter may only be achievable with a large budget or as part of major refurbishment or new build project.

It may be useful to relate these design measures to the various levels or building layers that exist in buildings, following the approach adopted by leading researchers in the field of adaptable design (Brand, 1995, Friedman, 2002). Brand describes these layers as the 'six S's' composed of 'site', 'structure', 'skin', 'services', 'space plan' and stuff (fixtures, furniture etc). Starting with 'site' and working up to 'stuff,' Brand describes how each layer becomes progressively less integral to the building, less fixed, and critically, less expensive to modify.

To provide a structure for the various design measures outlined in the research, we have organised them into five design scales. These design scales start with minor, low cost elements (i.e. labelling of food containers or signage to indicate toilet location) and work up to design measures that relate to fixed and more expensive elements (i.e. altering the spatial layout of a building, building a new extension or a new dwelling). This structure will support the proposed guidelines and allow users to select design features appropriate to needs, context (i.e. in an apartment setting it may not be possible to alter the structure) and budget. The proposed design levels include: 1) Labelling and Signage; 2) Assistive Technology (AT), Ambient Assisted Living (AAL), or Telecare; 3) Interior and exterior fixtures, fittings and finishes; 4) Building Fit-out; and 5) Spatial Layout and Structure.

As this research focuses primarily on the building elements and fabric of a dwelling, the costs associated with these five levels pertain largely to the impact of the various design measures on the physical dwelling. Therefore while the individual devices associated with AT, or AAL may be expensive in themselves, incorporating these into the physical dwelling may incur little cost.

These design levels are illustrated in Figure 21 and are discussed in terms of construction costs in the sections that follow.

Labelling &Signage	AT& AAL, Telecare	Interior & exterior F, F&F	Building Fit-out	Spatial Layout & Structure
€	€€	€€€	€€€€	€€€€€
min. / no cost	low cost	medium cost	high cost	highest cost
1	2	3	4	5
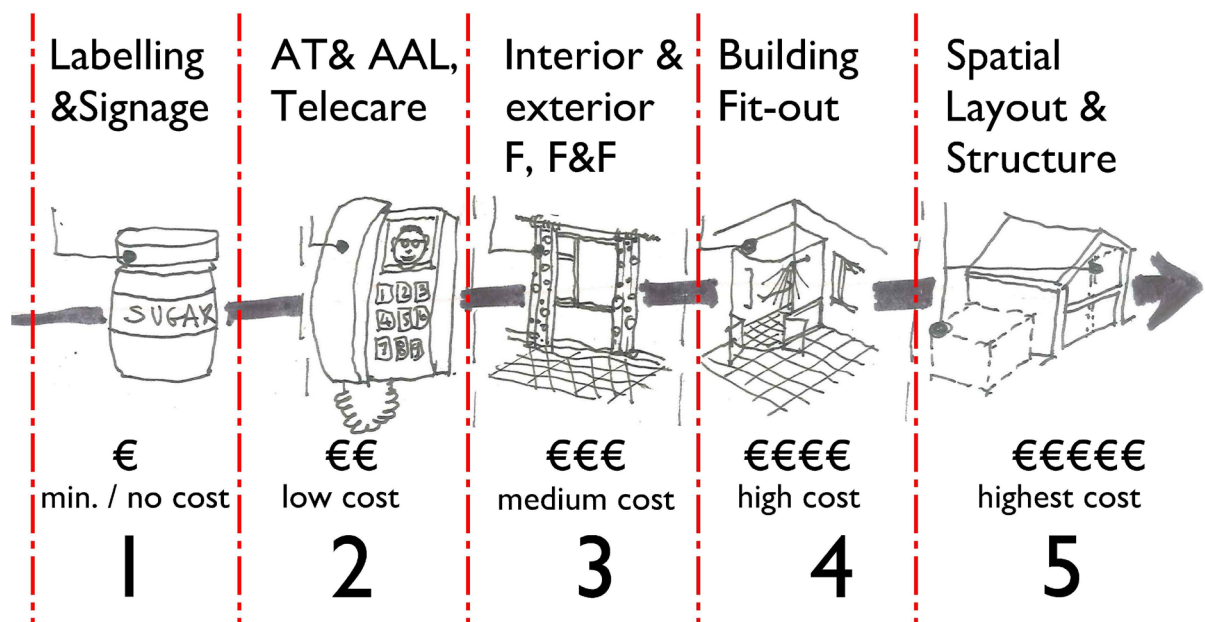
Figure 21 – Five Design Scales

5.11.1.   Labelling and signage

This includes a wide variety of measures ranging from simple labelling of food containers and reminder notes, to fixed signage indicating the location of important items or rooms such as the bathroom. Depending on the extent of the work carried out these may cost nothing or at most, in the case of professionally manufactured signage, have a minimum cost.

5.11.2.   Assistive Technology

AT can range from basic grab rails, to bath hoists, or devices to aid communication. In this context AT can be defined as "products/equipment oriented towards providing immediate functionality to support an older person or person with disabilities and/or their local carer"(Cullen et al., 2012.p.142). These authors describe AAL as "embedding intelligence into the everyday environment in order to provide assistance with everyday living for those that need it."(p.142), and define Telecare as the "provision of social care from a distance, supported by telecommunications" (p.141).

These systems vary considerably in cost depending on the specified equipment. However, in terms of costs to the dwelling itself, many of these technologies can be fitted or retrofitted without any major additional costs to the actual structure. In new build scenarios additional cables or higher specification communication cables, such as CAT6 cables, can be provided as

part of the electrical fit-out, for relatively little extra cost. Wireless technology options are becoming increasingly available and these may be useful in retrofit projects to negate rewiring in existing dwellings.

5.11.3. Interior and exterior fixtures, fittings and finishes:

As described earlier in Section 5.7, the use of interior colour, contrast and suitable surface materials for floors, wall and ceilings is crucial in achieving Universally Designed dementia friendly dwellings. In new builds it is easier to specify appropriate finishes and colours from the start. However in retrofitting dwellings it may be necessary to remove unsuitable finishes. For instance, glossy or patterned floor finishes may need to be replaced throughout the house with appropriate floor coverings. Depending on the quality of floor finish required this could cost up to €30 - €50 per M^2. Whilst this offers just one example, it provides an indication of the possible costs associated with retrofitting an existing dwelling to make it dementia friendly.

5.11.4. Building Fit-out:

Building fit-out includes windows, doors (including ironmongery), electrical and plumbing services, or alarm systems. Depending on the specific window design, there may be additional costs associated with having a lower window sill (for visual access). Also the use of extra wide internal doors, or 'cat and kitten' doors may also incur additional expense. Providing specific heating controls to avoid excessive interference by a person with dementia may also result in additional costs, although the solution may be as simple as locating the controls out of direct view or providing a cover to keep them out of sight.

5.11.5. Spatial Layout and Structure:

While the need for significantly larger dwellings has not emerged as a key concern, it is important to provide adequate space for general circulation, to manoeuvre wheelchairs, utilise AT such as bath hoists, or simply provide the space for carers (informal and formal) to assist with bathing or toileting activities. Providing the additional space has an obvious construction cost and can be roughly estimated using current construction cost indices. According to the Society of Chartered Surveyors Ireland (SCSI, 2013), current rebuilding costs in Ireland range from €1,714 sq. m for a detached bungalow (146 sq. m) in Dublin to €1,829 sq. m for a terraced house (70 sq. m). In the north-east of the county the same dwellings cost €1,167 sq. m and €1,277 sq. m respectively. These figures relate to basic quality estate-type houses and exclude fixtures and furniture. However as these figures represent rebuilding costs they include

demolition costs, professional fees incurred, and VAT on building costs (13.5%) and on professional fees (23%).

The SCSI figures quoted above relate to the full rebuilding of standard estate type houses and therefore the figures may be low. Building a one-off house, extending or carrying out works to an existing house would have a higher cost per sq. m. In 2006 the Royal Institute of the Architects of Ireland (RIAI) produced a consumer guide which outlined a range of construction costs. In relation to dwellings, this document quoted costs per sq. m in the order of €2,500 to €2,900 for one-off houses, €2,250 to €2,850 for basic single or two storey extensions, and €2,700 to €3,300 for single or two storey extensions with refurbishments to the existing dwelling (RIAI, 2006).

5.12 Key Recommendations

- The specific guidelines in the final guidance document will be drawn predominantly from the rich material reported in this chapter.

- The current Universal Design Guidelines for Homes in Ireland will operate as the parent document and it along with this report will be carefully scrutinised and cross referenced to avoid repetition and to ensure the successful use of both documents.

- There is a need for more research to be carried out on the use and usefulness of assistive technology and on the timing of when technologies in the context of the illness trajectory are most effective.

- There is a need for longitudinal research to investigate the changes people living with dementia encounter within their home over time and capture helpful data on the optimal point to introduce certain design interventions.

- There is a need for more research to be undertaken on the topic of the merits and demerits of open plan versus more traditional enclosed room layout structures. Proponents of open plan would argue that the latter promotes visual access, orientation and ease of mobility whilst those subscribing to the more traditional cellular plan, would favour it, in terms of its familiarity and its capacity to provide distinct spaces for distinct activities.

Chapter 6 – Case Studies

6.1. Introduction

Over the past two decades, several excellent books, reports and articles have been published which have brought together cases studies exemplifying best practice in approaches to the design of buildings for people living with dementia (Cohen & Day, 1993; Judd, Phippen & Marshall, 1998; Cox, 2006; Utton, 2007; Anderzhon et al., 2012). Examples also exist of case studies looking at the design of buildings for older people in general but which also include specific designs for people living with dementia (Housing Learning and Improvement Network, 2009). The focus in these collections of case studies has been on designing for groups of people living with dementia, with a particular emphasis on small-scale home-like living facilities. However, the case studies in these publications, while highly informative, refer specifically to residential long-stay care settings.

Case studies which relate as much as possible to domestic dwellings, where people with a cognitive impairment live independently are lacking despite the fact that most people with dementia live in their own homes. Indeed, it is ironic that there is no collection of case studies of domestic dwellings designed or retrofitted from a Universal Design approach for people living with dementia and their families and carers. Therefore, as part of this research on Universal Design for Dementia Friendly Dwellings we set out to identify examples of these types of buildings. However, finding suitable buildings or projects for inclusion as case studies proved difficult.

The search for case studies involved web-based searches, a review of published case study literature and consultation with experts in the areas of Universal Design and Dementia across a

range of countries including Ireland, The Netherlands, England, Northern Ireland and Australia. We found few buildings or housing schemes focusing on dwellings for people living with dementia that were not part of any housing with care scheme.[16] For that reason, we have had no option but to include in this chapter, case studies of housing with care schemes. These are dwellings intended to support people living with dementia to live independently within a supported living context. Because there are similarities between these and community based domestic dwellings, we would argue that case studies illustrating the dementia friendly design features within these settings will be useful for informing the current project.

The following criteria were used to select the final case studies; firstly we wanted to achieve a mix of case studies including single 'own door' dwellings with multiple rooms, and one room en-suite units as part of a larger complex; secondly we wanted to be able to visit as many of the case studies as possible in person and speak to both the residents and management; and thirdly we wanted case studies from the Republic of Ireland, from Northern Ireland and at least one from continental Europe.

6.2. The case studies in outline

The resulting case studies drawn on in this chapter include a Dementia Model House based in The Netherlands, two examples from Northern Ireland, and one from the Republic of Ireland.

The first case study chosen is the Dementia Model House in Woerden in the Netherlands. This case study differs from the others in that it is a demonstration model. However, in our view, it reflects best practice in designing a home for people living with dementia and their families and carers. We have not visited in person this case study but have collated the information based on our web-based searches, literature search and consultation with experts (van Hoof et al., 2013).

We were keen to show examples of best practice from the island of Ireland. The next two case studies, namely Barn Halt Cottages and St Paul's Court, are located in Northern Ireland. Both of these case studies involve individual dwellings in an assisted living setting. The fourth case study, Anam Cara, is located in the Republic of Ireland. Whilst Anam Cara does not contain independent dwellings in the same way as Barn Halt Cottages or St. Paul's Court, it exhibits

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[16] Housing with care schemes are also referred to as supported housing schemes.

several design features which we believe will help to inform this research. For this research study, we visited the three schemes on the island of Ireland.

These four case studies represent building designs that focus particularly on people living with dementia. Each case study commences with a brief description of the dwelling or "housing with care" scheme. It provides information about the key planning or design features used in these dwellings for people living with dementia and their family caregivers. A drawing of the floor layout is included in each case study along with images illustrating key features.

6.2.1. Dementia Model House

Location - Bezoekadres modelwoonwijk, Korenmolenlaan 4, 3447 GG Woerden, The Netherlands
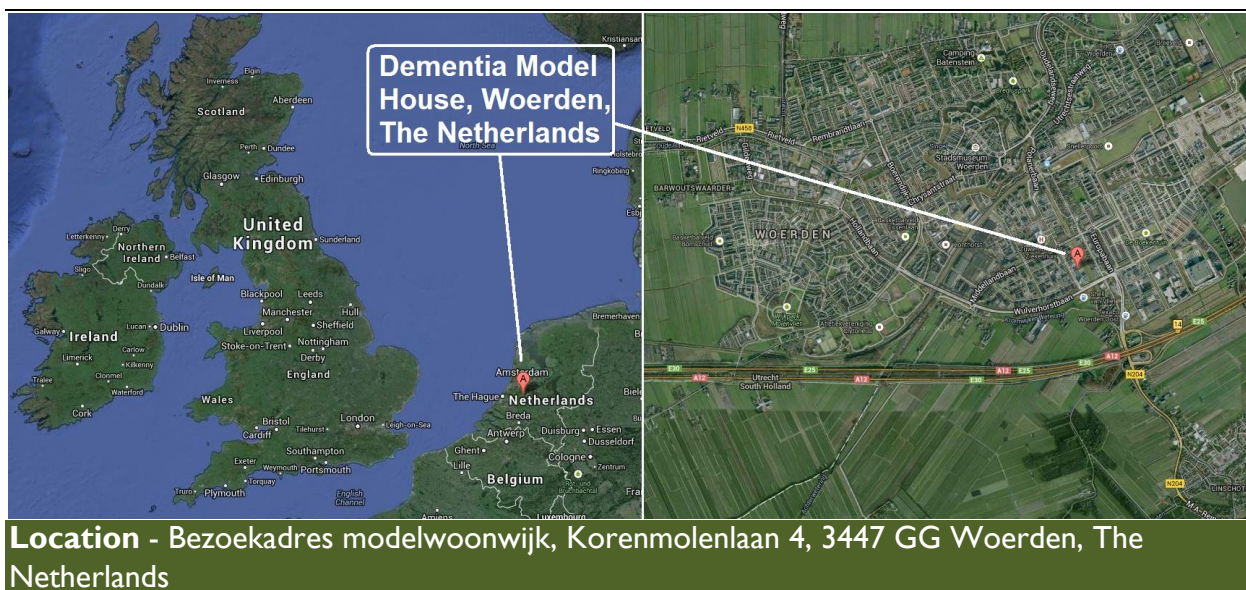
Project Description

The Dutch Dementia Model House is the result of collaboration between Hogeschool Utrecht, OTIB[17] and Alzheimer Netherlands. It opened in the Netherlands in April 2012 and was developed under the project titled - *Technology@Home! (Technoligie Thuis Nu)!* (www.technologiethuis.nu).The overall project was built as an enclosed structure forming an indoor miniature neighborhood. This enclosed neighborhood comprises four houses which serve as a test bed for the building services sector to explore innovative technological solutions to meet the needs of different groups of people and help them age in place. The project demonstrates the importance of the building services sector for health care and provides a valuable resource for housing associations, education and future residents.

One of the dwellings in this project was designed specifically and developed as a home for people with dementia and their family members. This project is described in detail in van Hoof et al. (2013). Images as shown below are taken from that publication.

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[17] Training and Development or Technical Intervention Uneto-Vni.

Figure 22 – Image 1 shows visual access to the toilet. Image 2 shows a large button format telephone
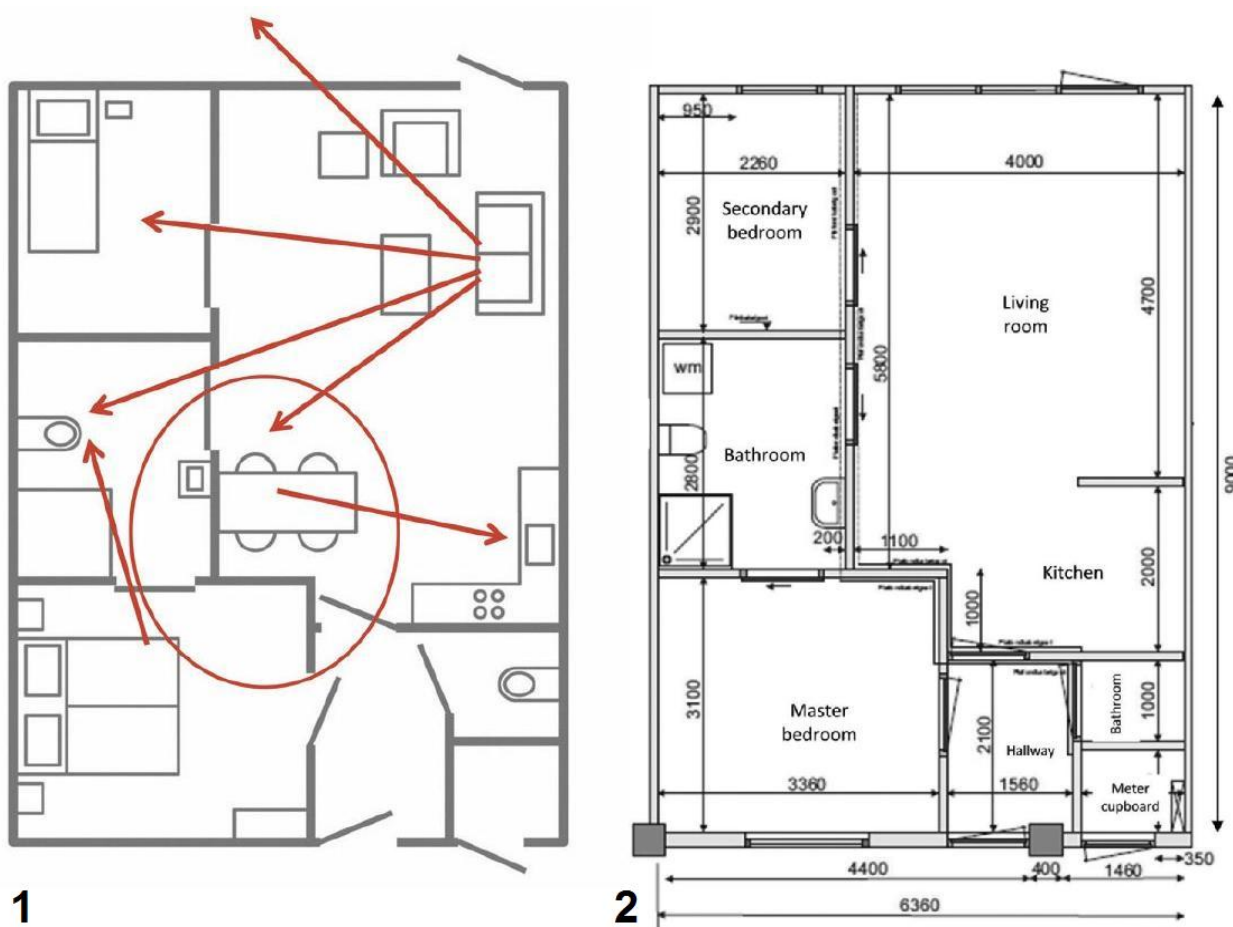
Key Design Features

Figure 23 – Image 1 illustrates visual access and circulation. Image 2 shows the detailed layout (van Hoof et al., 2013)

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Planning and design features

- The principle of good visual access is in evidence here. Open and accessible floor plans and sliding doors with good sightlines for visual access to key areas are visible within the dwelling (see Figure 23). The layout has been designed to provide an overview of the entire dwelling. Residents and carers can keep each other in sight. This is important particularly in cases where a person living with dementia feels anxious when left alone and may shadow the family caregiver for security reasons. The sliding doors can also be closed depending on the needs of the users and the level of privacy required, for example when family members, friends or neighbours are visiting. The doors are also designed so that when they are opened they create a circular walkway for moving about in a safe space without dead-ends.

- The second bedroom has been designed with a retreat area for either the person living with dementia or their partner or carer.

- The living area is immediately adjacent to the kitchen and again is well positioned to stimulate the senses. It allows for cooking smells from the kitchen to provide olfactory stimulation for the person living with dementia who may be sitting in the living room. It also facilitates interpersonal contact between residents.

- The dwelling is fitted with a bathroom for the residents, which is directly connected to the main bedroom, while the WC off the hall is primarily for guests.

- The living area provides direct access to a garden to encourage residents to go outdoors.

Detailed design, finishes and technological features

- In case of emergencies, the external front door has a keypad entry for carers. Beside the key pad, a standard doorbell is located (see Figure 24). The external door handle is cleverly designed with a 'senior lock', where the keyhole is situated above the door lever arm to ensure it is more visible. Internally, a curtain is available which can, if necessary, be drawn to disguise the front door and remove it from sight thereby reducing the desire to leave the premises on the part of residents who may be agitated or wish to exit unaccompanied.

Figure 24 – Image 1 shows a key pad and a more traditional bell. Image 2 shows the curtain which can be drawn over the coat rack and the front door (van Hoof et al., 2013)

- The common hallway outside the apartment contains an external meter cupboard which is a centre point for all utilities such as gas and electricity. This places these potentially hazardous utilities in a safer location external to the living space. Their allocation is such that they can be easily reached by service workers without necessarily disturbing the resident(s).
- There are no thresholds at any of the doors to avoid a person perceiving it as a step. The floor is finished with easy maintenance timber flooring, which does not have a strong pattern. In general the design seeks to create a safe and easy to negotiate clutter free environment.

Figure 25- View to main living area (van Hoof et al., 2013)

- Higher lighting levels are provided for increased safety and to compensate for decreased vision and additional light sources are included to increase visibility. Two ceiling mounted lights, which emit light with a colour temperature of 6500K (cool bluish light) to provide light therapy, are fitted in the main living area.

- The main bathroom is equipped with a bath and a level access shower[18] that allows maximum freedom of movement for a carer (either informal or formal). The toilet is carefully designed with a black toilet lid, a white ceramic height adjustable WC, fitted to a blue tiled wall. These different colours provide good visual contrast and serve to help those who might have orientation problems. The approach used also compensates for those with perceptual problems.

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[18] A level access shower contains no threshold or change of level between the bathroom floor and the floor of the shower. The shower floor is either formed by a level access shower tray or tiles which are continuous with the tiled bathroom floor.

Figure 26 – view to bathroom showing colour contrast between WC and wall (van Hoof et al., 2013)

- Large windows enhance visual access to the exterior and provide good levels of daylight, while solar blinds are fitted to reduce glare and counteract any uncomfortable rise in temperature (See Figure 26).

- There is under-floor heating throughout the dwelling to eliminate wall hung radiators, which can be problematic in terms of falls or burns. There is a radiator in the bathroom for drying towels. The radiator also helps to dry any wet patches on the floor.

- A smart cooling system programmed to operate during periods of high temperatures (above 25 degrees). This protects the occupant against the detrimental effects of hot summers and dehydration, thereby minimising the threat of wandering and agitation.

Discussion

This Dutch demonstration project is purely a demonstration model and is not occupied. It can be visited by design professionals to enable them observe first hand various dementia friendly design features. The dwelling integrates various dementia features in a holistic way and is uniquely designed to serve not only the person living with dementia, but also critically other family members or carers. In many ways, this dwelling is suitable for any person and features such as the visual access or the circular route would also be very useful for residents with small

children. The flexibility afforded by sliding doors, which allow for opening up space or closing

this off, is a valuable feature that would be welcomed by most people.

6.2.2. Barn Halt Cottages
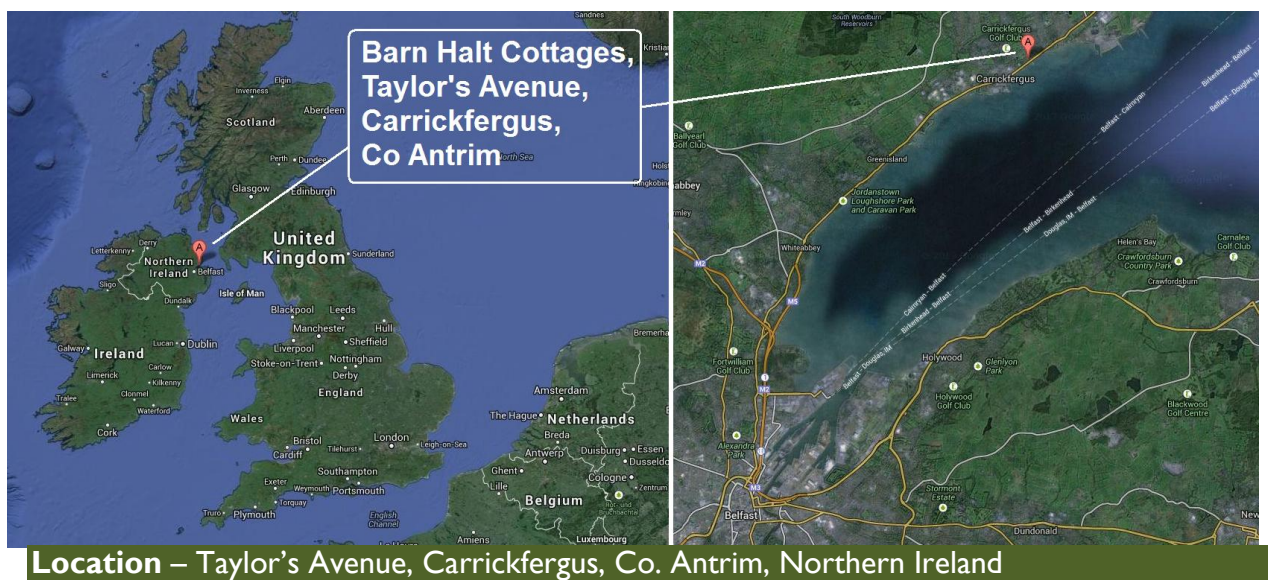
Location – Taylor's Avenue, Carrickfergus, Co. Antrim, Northern Ireland

Project Description

Opened in 2007 and located on the outskirts of Carrickfergus, Barn Halt Cottages is the result of a joint initiative involving the Northern Ireland Health and Social Care Trust (Homefirst locality), Fold Housing Association and the Northern Ireland Housing Executive. Barn Halt was specifically designed for older people including people living with dementia and their family members and provides tenants with the opportunity to maintain their independence and links with the local community. It has a total of 26 cottages; 16 one-bedroom; 8 two-bedded (for two people); and two other two-bed cottages (for three people).

Figure 27 – Exterior view of Barnhalt Cottages, Carrickfergus, Co. Antrim

Each cottage has its own front door but is connected via a backdoor to a common circulation area formed by a corridor. The latter connects with communal facilities (e.g. common sitting areas, sitting room, activity rooms, coffee docks, hairdressers, laundry room). This communal part of the scheme also houses the onsite management and care staff along with a variety of care facilities.

Key Design Features

Wood effect Linoleum

Non slip Linoleum

Threshold / change in material at all doors and in kitchen / living area

Carpet

Enclosed courtyard for sitting out which provides safe and secure gardening space

External garden, entrance and parking area

Independent front door

Front door

bathroom

living room

Carpet

Linoleum
kitchen

Carpet

Bedroom

Courtyard

Tiles

Back door

Main circulation spine

Extra wide internal doors and circulation space for ease of circulation

bathroom with dual access form bedroom and the hallway

Link corridor providing access to main circulation spine and access to courtyard

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Figure 28 – Floor plan of typical 1 bedroom unit (plans are not to scale and are indicative only)

Planning and design features

- The cottages are located close to transport systems and shopping facilities, which promotes independence and facilitates residents to remain part of the local community.

- The architectural design of Barn Halt Cottages is purposely traditional. It mirrors that of old-style railway cottages which integrates neatly into the community and adjacent railway line. For the residents who live there this taps into long term memories, the potential for reminiscence, and provides links to the past and a sense of belonging (See Figure 29)

Figure 29 – Exterior view of Barn Halt Cottages, Carrickfergus, Co. Antrim

- Each unit is provided with small courtyard space that can be viewed from the circulation area. This brings light into the unit and to the circulation area and safe courtyard spaces.

Figure 30 – Typical courtyard spaces in Barn Halt Cottages, Carrickfergus, Co Antrim

- The internal layout of each unit comprises an open plan kitchen, dining and living areas. When the doors are left open there is a direct view of the bathroom from the living room.

Detailed design and technological features

- For ease of recognition, the front doors of the cottages are painted in a variety of bright colours. Landscaping details and planting also provides another level of personalisation and the possibility for residents to engage in meaningful and socially engaging activities such as gardening or enjoy outdoor living.

- The back doors which open onto the main circulation are painted a bright colour in contrast to the wall. However, painting the doors in a range of different colours would have helped to distinguish one door from another and would have aided people living with dementia to recognise their own front door (See Figure 28). It is good practice to paint doors contrasting colours to provide more visual cues for people living with dementia and aid recognition.

- Residents are encouraged to personalise and decorate their own dwellings. Figure 31 shows internal images of a typical cottage decorated according to the taste of the individual resident allowing plenty of scope for personalisation. Image 1 below also shows the line of vision to the WC from the bedroom and the dual access to the bathroom provided from the hallway and the bedroom. Figure 26 shows this sightline, along with a sightline from the

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living area to the bathroom, when the doors are left open. Beyond this there is little visual access between the living and bedroom area.

- A feature not usually recommended for dementia friendly dwellings are the patterned carpets and the distinct junction between the carpet and the wood effect floor at many thresholds. In addition, the wood effect floor is quite glossy and produces a glare in direct sunlight. While there is good colour contrast between the floor and the walls, there is little contrast between the walls and the internal doors. Lower sills in the living area (See Figure 31, Image 1) would give greater visual access to the outside.
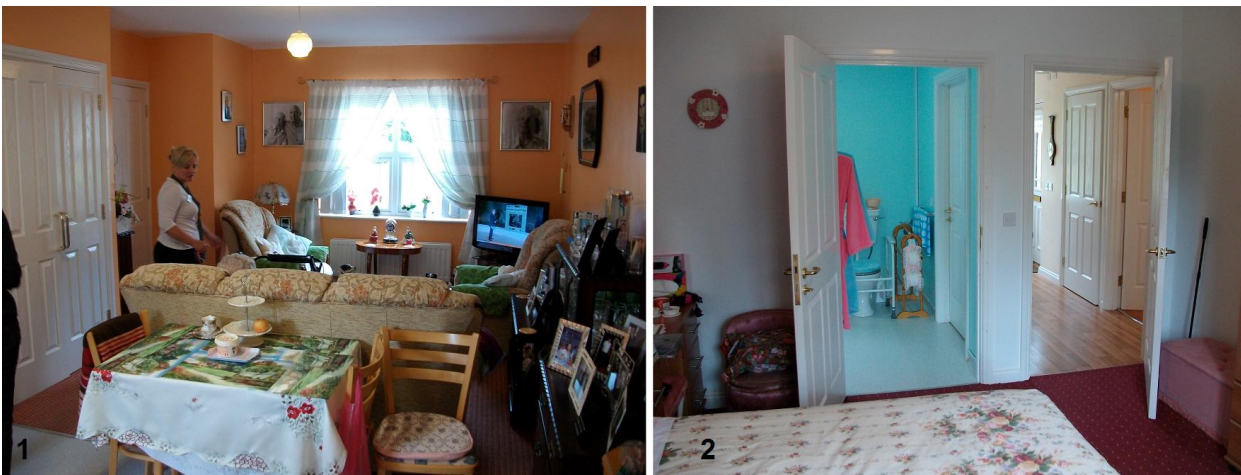
Figure 31- Interior of typical cottage, Barn Halt Cottages, Carrickfergus, Co. Antrim

– Image 1 shows the living area of a typical unit. Image 2 shows the bedroom with views to the hallway and bathroom

- The floor finishes in the main circulation area are plain colour and without patterns. The floor colour also provides a good level of contrast to the walls (See Figure 32).

- All windows in these circulation areas have low sill heights and therefore provide good visual access to the outside spaces and maximise natural light (See Figure 32).

Figure 32 – Image 1 shows the low level sill and notice boards. Image 2 shows the brightly painted front doors

- The windows, pictures, notice boards and signage on the walls in the circulation areas linking cottages act as cues and help the residents with orientation and way-finding.

- The signage shown in Figure 33 provides directions to each unit. Referring to each unit as a 'house' promotes normalisation and may help to promote a better sense of personal identity. However, the reflective surface of the signage renders them hard to read and may cause difficulties for a person with visual difficulties.

Figure 33 – Signage providing direction to residents, cares and visitors to cottages

- Assistive technology provides unobtrusive monitoring in a totally dignified manner. Devices such as door exiting alarms, fall detectors, helplines, pendants and speech units are in operation to ensure residents can feel safe and remain as independent as possible.

Discussion

In many ways Barn Halt is a very innovative development and provides residents with a unique opportunity to live independently whilst at the same time having access to many services available in the main building. The individual units are quite spacious and allow for much personalisation according to an individual's preferences. The external spaces are also very appealing and well maintained (See Figures 29 and 28) and with the addition of the rear courtyard the resident is well served with external space. It could be argued though that the benefit of these spaces has not been maximised by the visual access provided from the internal spaces. If the living room and the bedroom window sills were lower they could provide a better view into these spaces and thus provide additional positive stimuli and encourage residents to use them.

6.2.3. St. Paul's Court

Location –Lisburn, Co. Antrim, Northern Ireland

Project Description

St. Paul's Court is a purpose built supported living unit for people living with dementia. The original scheme's accommodation, opened in 2004, consisted of 15, 2-bedroom bungalows providing support to people living with dementia. The recently opened (2009) new building caters for people living with either mild or moderate dementia. It consists of self-contained apartments built around a large open plan room or atrium.

Figure 34 – View to the front entrance of a typical bungalow

Located in a quiet residential area on the outskirts of Lisburn, Co. Antrim, St. Paul's Court aims to enable people living with dementia who require "housing with care" support, to live

successfully in the community. The entire building structure of St Paul's was built over two different stages or phases and is currently managed and operated by Praxis Care.

Key Design Features

Private Garden

Direct Access to enclosed garden area

Low level bay window provides good interaction with outside

Door fitted with magnetic keypad door alarm which relays message back to management if a person leaves the dwelling

living room
Carpet

Front door

Bedroom
Carpet

Guest bedroom

Extra wide internal doors and circulation space for ease of circulation

Threshold / change in material at kitchen and bathroom

Good visual access to all parts of the dwelling

kitchen
Linoleum

Linoleum

shower

Bedroom
Carpet

Plain colored carpet in living room and bedroom

Direct Access communal courtyard

Back door

Courtyard

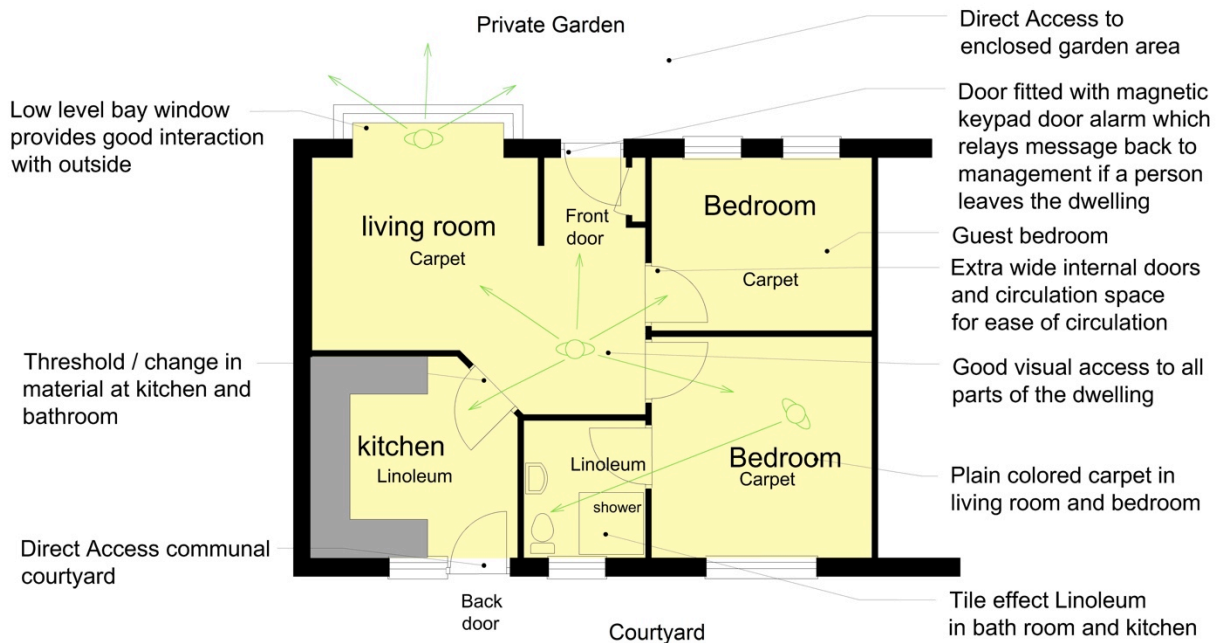Tile effect Linoleum in bath room and kitchen

Figure 35- Layout of a typical bungalow in St Paul's Court

Planning and design features

- The two bedroom bungalows are arranged in semi-detached and terrace units around an elongated central courtyard along a North - South axis. Each unit opens directly onto this secure courtyard and is also provided with a small enclosed rear garden. (See Figures 36-37)

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Figure 36 – View to central courtyard

Figure 37 – View to rear gardens

- The layout of each bungalow allows for an open plan arrangement to be created when doors are left open (See Figure 35). This creates good visual access throughout the dwelling in a similar manner to that achieved in Woerden. There is also a direct line of vision to the WC from the main bedroom. The bay window adjacent to the front door also provides good wide angle views into the garden space. There are no corridors and all rooms open into the living area through extra wide doors thus providing greater accessibility.

- A second bedroom can function as a guest room or bedroom for a carer, or simply a retreat space for either a carer or family member, or the person living with dementia.

Figure 38 –Main living area of a typical bungalow in St. Paul's Court, Lisburn, Co. Antrim

Detailed design and technological features

• While the area has a plain coloured carpet both the bathroom and the kitchen are finished with tile effect linoleum which creates an unwanted colour contrast at the thresholds where these material meet.

• There is a weak colour contrast between the floor and walls but a good contrast between the wall and the internal doors.

**Figure 39 – Image showing colour contrast between floors and walls and between walls and internal doors**

• The bathroom is fitted with grab rails and a wet-room shower for maximum accessibility.
• All occupants are encouraged to use their own furnishings to create a sense of familiarity.
• Each bungalow has a fully fitted kitchen with partially glass-fronted cupboards

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- The front door is fitted with a magnetic keypad door alarm which can relay messages back to the managers should a door be opened at an unexpected time.

Discussion

The layout and design of each bungalow provides many positive design features for people living with dementia; the provision of secure courtyard space and the individual private gardens provides a good choice in terms of private and semi-private open space. However, as seen in Figure 36 the central courtyard has very little soft or hard landscaping and would not be conducive to social interaction. This space could be utilised better by providing softer and harder landscaping along with garden furniture which would provide an attractive central space for residents to sit out, interact, or do some gardening.

6.2.4. Anam Cara
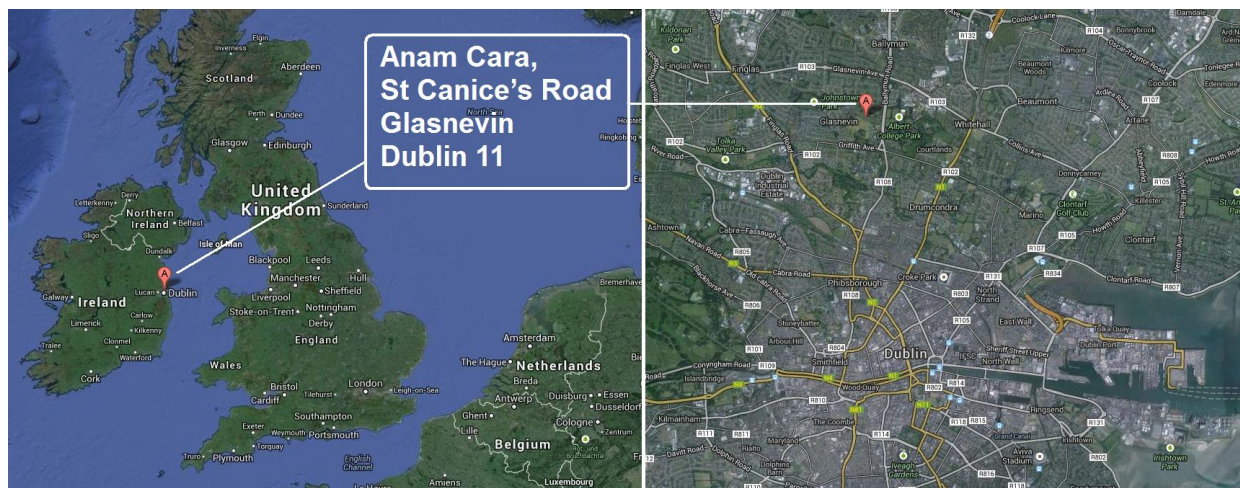
Location – St. Canice's Road, Glasnevin, Dublin 11, Ireland

Project Description

The Cherryfields "Housing with Care" scheme opened in Clonsilla in Dublin 2006. A year later (2007), Anam Cara, the scheme that is described below, opened in Glasnevin on the north side of Dublin. Both schemes operate under the joint auspices of Fold (a private not-for-profit provider) and the Health Service Executive. Anam Cara contains 28 units for people living with dementia and a further 28 units for older people who are in need of 24 hour care and support.

Figure 40 – View to Front entrance of Anam Cara

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Unlike St Pauls' Court and to some extent Barn Halt, Co. Antrim, Northern Ireland, the dementia friendly units provided in the Anam Care scheme are not independent dwellings but the scheme is included as a case study in this report because there are elements of the units and the overall development that provide useful insights into dementia friendly design.
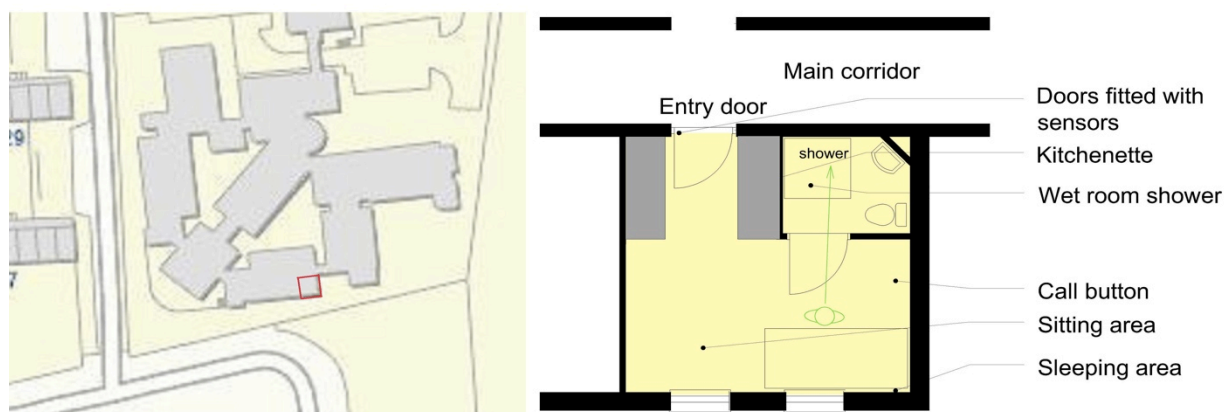
Key Design Features

Figure 41 – Typical layout of a ground floor unit in Anam Cara

Planning and design features

- The design of the overall building complex is based on a series of wings within which are located two enclosed internal courtyards. These courtyards provide residents with safe, secure and sheltered outdoor spaces. The internal circulation is designed so that there is a continuous route with minimum dead-ends.

- The individual units are located on either side of the circulation corridor and comprise one spacious bedroom with a kitchenette, sitting area and an accessible bathroom with a wet room shower.

Detailed design and technological features

- In the circulation areas a plain coloured carpet provides good visual contrast with the walls while the doors are painted bright colours which are distinct from the wall. Each wing has its own colour theme to help orientate the residents and this theme is picked up on in the carpet colour and on the doors (See Figure 42). However, the fact that all doors in any one corridor are painted in the same colour (in line with the theme) may be confusing for a person living with dementia and perhaps even to family members and staff. This is at odds

with the practice of painting individual doors in contrasting colours to provide more visual cues and aid recognition.

- This design feature is coupled with the extensive use of 'Memory boxes' at all front doors to provide a level of personalisation and help individuals to identify their own doors (See Figure 42 Image 2 and a 'Memory box' in more detail in Figure 43)

Figure 42 – Image 1 shows the orange themes corridor while Image 2 shows the green theme

Figure 43 "Memory Box" at the entrance to a dwelling in Anam Cara

- All corridors are also fitted with brightly coloured handrails which provide support for a person that may be frail or guidance for a person who may have a visual difficulty.

- One interesting feature used in the circulation area is a bus stop sign. The thinking behind this is that the sign provides a visual cue to stop, sit down and wait for a while (See Figure 44)

Figure 44 – Bus stop sign along the circulation corridor

- A 'Snoezelen' or multi-sensory room is available for residents for relaxation purposes. Through the use of soothing colours, tactile materials and led lighting, a calm environment is created in this room (See Figure 45)
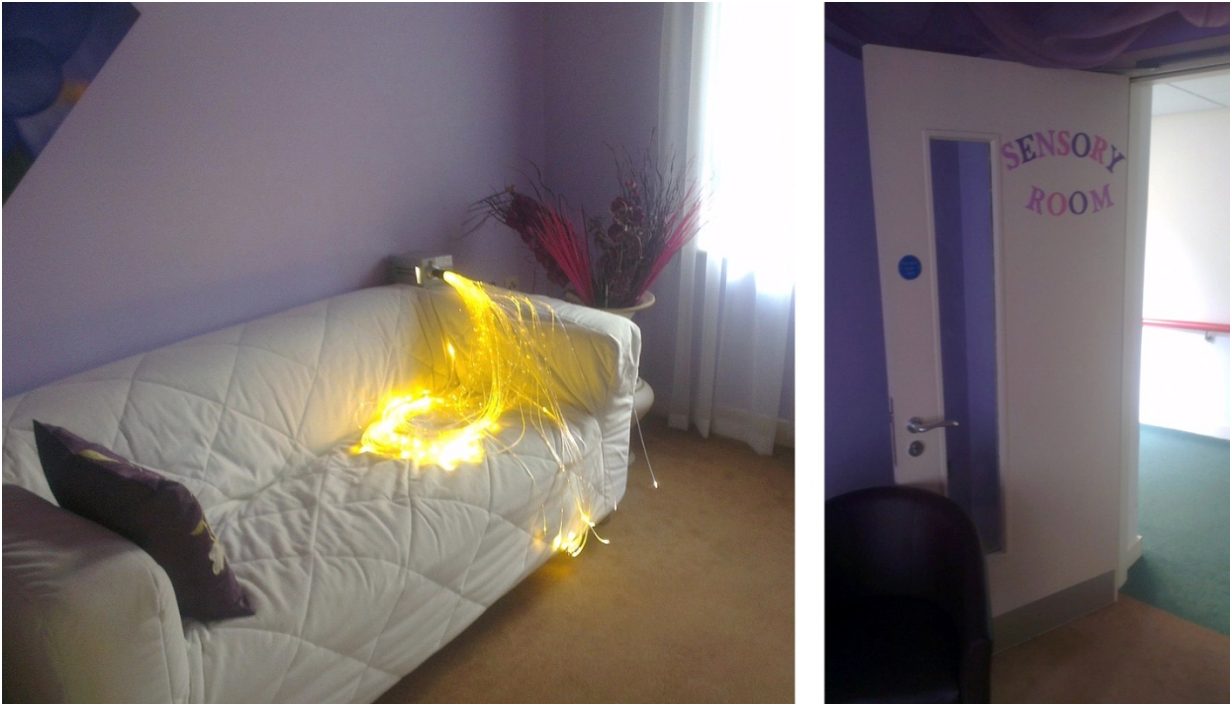

Figure 45- Soezelen or multi-sensory room

A display area with a large format clock and large printed text displaying the date, month and season is provided in the communal area to help orientate the residents

Figure 46 – Noticeboard with large format clock, day, date and the season to orientate residents to time.

Figure 47 – Communal kitchen area

- A number of small scale communal kitchen and dining areas are provided to create a more domestic atmosphere. Signage is fixed to the front of the kitchen units to indicate their contents (Figure 47)

Discussion

While Anam Cara does not contain independent or 'own door' units, and typically compared with the other case studies, caters for people at a more advanced stage of dementia, it serves to illustrate many significant ways in which design can support people living with dementia. The continuous circulation route and the 'bus stop' as a place to stop and rest, demonstrate the need to provide space and an opportunity for people to walk in a secure environment. The use of colour and the provision of a sensory room highlight the relevance of sensory stimuli. Good use is made of 'Memory boxes' for personalisation and for the purpose of reinforcing self-identity. While the colour themed corridors may help with overall orientation within the complex, the use of contrasting colours would be better than painting all doors within the corridor the same colour would be a useful addition to help with orientation.

6.3. Conclusion

Apart from the Dementia Model Home in Woerden, the Netherlands, all of the existing case studies introduced in this chapter broadly speaking relate to long-stay "housing with care" settings. This highlights the fact that to date little attention has been paid to the design or retrofitting of domestic dwellings with a view to ensuring that they are dementia friendly. Nevertheless, each of the case studies in this chapter includes a wide variety of design features that are key components in creating dementia-friendly dwellings from a Universal Design approach.

The Dementia Model House in Woerden and the dwellings in St. Paul's Court provide flexible arrangements which can be opened up or closed off pending the needs of the residents. We consider this to be a clever use of design. The use of colour is dominant in all schemes but in some cases as argued in this chapter not used to its full potential. For example, in Anam Cara the use of different colours for adjacent doors would further aid with orientation. The optimum use of outdoor spaces varied. For example, we pointed out that lower window sills in sitting rooms at Barn Halt would improve the visual access to the appealing outdoor spaces and we argued that the external front courtyard in St Pauls' Court is an under-utilised resource. Providing good visual access to external spaces is important because it can be stimulating for a person with dementia if there is something interesting to see when looking out of the window as opposed to sitting with nothing to look at (DSDC, 2013; Pollock & Marshall, 2012). Assistive technology was found to be an integral feature in each of the case studies.

This chapter has provided useful examples of three different housing schemes offering support to people living with dementia, two were located in Northern Ireland, one in the Republic of Ireland and one model home in the Netherlands. The Case Studies demonstrate that up-skilling architects and interior designers with relevant knowledge about the effects of dementia on people living with the condition, and on their informal and formal carers, enables designers to design buildings and living quarters which are discreetly planned to compensate for the disability of dementia and promote more independent living. We have selected these case studies as each illustrates several different features of design which if emulated would most likely improve quality of life for people living with dementia, their families and carers. Our review has also at times been critical of some aspects of these housing schemes. However, as a concluding remark and based on these case studies we must stress that we the researchers do

not live in these dwellings and therefore are not the experts. It would be useful to get the views of residents with dementia, their families and carers about the schemes reviewed.

6.4. Key Recommendations

- Since the case studies only covered housing with care schemes and a model house, it would be helpful to undertake some case studies in the future with people who have mild to moderate dementia, their families and carers living and working in homes that have been adapted to accommodate their condition to better understand what has worked well and what has failed. Such experiences could then be shared with others.

- Further work to progress the Universal Design of dementia friendly dwellings could be undertaken. In particular there is a need to conduct a pilot study of a selection of different dwellings adapted for people living with dementia, their families and carers and which would incorporate pre-determined universally designed dementia friendly features. An evaluation study of this type could use a pre-test, post-test design and would generate helpful information about the success or otherwise of design features. A study of this kind would need to be given careful consideration and carried out in close collaboration with people living with dementia, their families and carers and with relevant health service professionals such as occupational therapists and case study officers.

- Further consideration could be given to the design and development of a demonstration unit or dwelling (similar to the Dutch model described in this chapter but adapted to suit the cultural and social needs of people living and working in Ireland). This could be undertaken with input from or in collaboration with people living with dementia, their families, carers, relevant health service professionals, social and behavioural scientists, architects, design engineers and technology experts. This demonstration unit could act as a research and education resource to inform the relevant disciplines about key Universal Design dementia friendly practices, features and technology.

Chapter 7 – Stakeholder Engagement

7.1. Introduction

From the outset, a central component of the research was to engage with a wide range of stakeholders including people living with dementia, their families and carers. The reason for this was to ensure that the research report and its recommendations and the Universal Design Guidelines for Dementia Friendly Homes would be fit for purpose and would meet the actual needs of people living in the community with dementia, along with the needs of family members. Stakeholder involvement included one-to-one or group interviews with people with dementia and their family caregivers and people drawn from a wide range of key organisations. In addition, two workshops were hosted for stakeholders. This chapter presents the findings from this stakeholder engagement process.
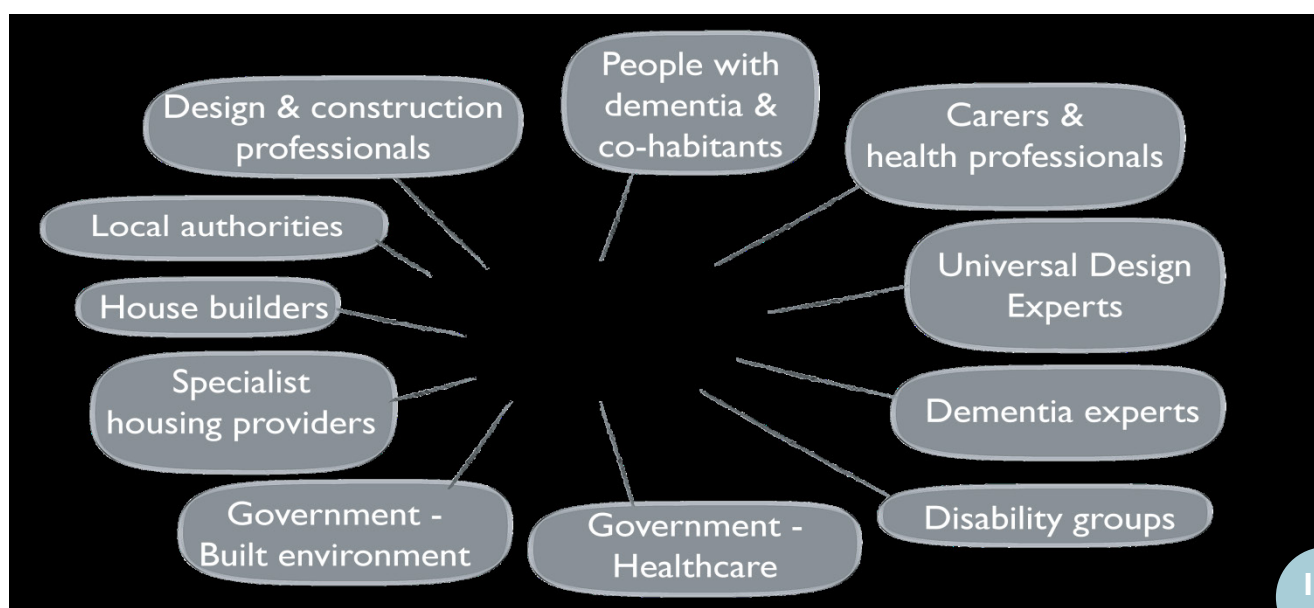

Figure 48 – The range of stakeholders participating in this project

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7.2. Stakeholder interviews

Interviews were held with 38 individuals from a range of stakeholder organisations including: representative organisations of people living with dementia, older people and people with disabilities; government departments; local authorities, housing providers, the HSE, allied health professionals, architects, landscape architects and house builders. People living with dementia, their family members and carers were also interviewed. The key themes emerging from those interviews are presented below:

7.2.1. Awareness and knowledge of dementia and perspectives on Universal Design for dementia friendly dwellings

There was much variation amongst stakeholders regarding their understanding and awareness of dementia. Not surprisingly, those who worked closely with people living with dementia and those with expert knowledge of designing or adapting buildings for people living with dementia had good knowledge of dementia and most also had a relatively good understanding of Universal Design for dementia friendly dwellings. However, a sizeable proportion of the stakeholders including many of the architects, other building design professionals and housing officers participating in interviews (apart from those that had relevant healthcare design experience) had very little knowledge about dementia, or of ways of looking at dementia or the kinds of supports needed to live well with dementia. Typical responses were as follows:

> "Where do you see people with dementia?" (Stakeholder question)

> "What is the difference between dementia and Alzheimer's disease?" (Stakeholder question)

> "I personally wouldn't have … a huge knowledge about what … I might have some but not any significant knowledge of what is, what makes it easier for someone with dementia living in a house" (Stakeholder comment)

Amongst stakeholders, there was widespread reference to the concepts of accessibility, ageing in place and lifetime homes. Many stakeholders referred to the building regulations, their role in ensuring that more dwellings were wheelchair accessible and the improved accessibility of new houses, and in particular the inclusion of a downstairs toilet and accessible doorways.

"Well when you are doing the spec for your house now they will always specify that
you have to have a downstairs toilet that is wheelchair accessible" (stakeholder).

"… one of the biggest issues around Part M, people think so much in terms of
wheelchair accessibility, it is about accessing and using the building and it is very hard to
get people to move away from thinking about it in that way" (stakeholder)

There was much support for the principles of Universal Design and the view of one
stakeholder was to: 'design housing to a high level of Universal Design and make it adaptable
for specific needs'. However, stakeholders' understanding of Universal Design was not
ubiquitous:

"Universal Design has been around for a long time but not everybody is aware of it or
understands it and it is not that they are not on board but they just don't know about it
or know enough about it and how all of us disseminate information and it filters down I
think it could still be improved"

Some were more acquainted with using a Universal Design approach for designing/adapting
dwellings for people with physical disabilities, or visual difficulties. There was less awareness
and understanding amongst stakeholders of using a Universal Design approach to design or
retrofit dwellings for people living with cognitive impairments or dementia and their families
and carers. According to one stakeholder, 'It's about the proper planning of communities'. One
stakeholder spoke about designing for dementia by default, for example, colour coding different
floors in a supported housing scheme or placing distinctive pieces of furniture at the end of a
corridor leading to residents' rooms. It was when discussing Universal Design for dementia
friendly dwellings that she realised that these could be considered to be design features that
would provide visual cues and help with orientation for people living with dementia. One
daughter admitted that, when adapting her mother's home for wheelchair use and sight loss, it
had never occurred to either the family or the builder they had engaged, that the changes being
made to the dwelling to accommodate her mother's needs would have an impact on her father
who also lived there and who had dementia:

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"Well the fact is we didn't actually look at that. We more looked at my mother
because we were like she's going to need a wheelchair and then her eyes and

we wanted it as much open plan as possible" (daughter of a man with

dementia).

There was a general consensus that the guidelines would need to provide for an understanding of dementia from a Universal Design perspective. In general, stakeholders were broadly in favour of education and training for all those who have a role to play in policy-making, planning, design, building and adapting dwellings for people living with dementia and their families and carers. However, awareness-raising and training were not viewed by all as a panacea. According to one stakeholder, 'house builders will largely respond to two things, the market and regulations (i.e. when it is economically advantageous or when they have to)'.

7.2.2. Familiarity as a key principle in Universal Design for dementia friendly dwellings

Many stakeholders highlighted the differences between newer and older dwellings regarding accessibility:

"I think the thing about it, is most modern houses have to be built to spec with access for disability and rooms are wide enough and doors and there's a toilet. You don't really get it in older houses or council houses or whatever which were purpose built for what they were. That is really where the difficulty lies" (stakeholder).

It was argued that the slowdown in house building could mean that retrofitting existing dwellings including those provided by local authorities and voluntary housing associations, to make them more suitable for people living with dementia, their families and carers would perhaps become more significant than building new dementia-friendly dwellings. As one stakeholder said- "it is important to look at where the market is going in the long run … of course retrofit is a key issue'.

Retrofitting properties can restore some of the design inadequacies of dwellings. However, a few stakeholders were of the view that older people can be resistant to change and want to 'make do with what's there', which they believed makes changing the environment problematic. Moreover, many more stakeholders highlighted the difficulties that adapting a dwelling can

present for a person with a cognitive impairment or dementia. One major difficulty is that the dwelling may no longer be familiar to the person, when the space is rearranged. For people living with dementia, this can have a negative impact on their experience of certain spaces within the homes, especially if the person has not been adequately consulted about the adaptations process. For example, a daughter of a man living with dementia explained that 'He knew where everything was like' but after extending and opening up the house downstairs to accommodate her mother who had become wheelchair bound, she reported that:

> "He'd be like 'Where's the bathroom? Where's the? ... Jesus this house is...'
> He thought that this house was huge because it was very open. It was very open
> like for my mother and he thought the house was huge and he wanted me to
> put up a wall or put a door up between the kitchen and the living room and I
> felt you can't, it had to be open, it had to be fine for Ma and that but he wanted
> a wall going up" (daughter of a man with dementia).

This case highlights the challenges involved in designing or retrofitting a dwelling for a person with a physical disability to make it accessible (this woman was wheelchair bound), when that person is co-resident with a spouse who has a cognitive impairment – in this case her husband had dementia.

Another example of the impact that major adaptations to a dwelling had was given by a wife of a man with dementia. After extending the ground floor of the dwelling to accommodate a downstairs bathroom and bedroom, she reported that:

> "Oh, he was so confused ... with doors. It wasn't his house at all. Yeah, he was
> in a different house. 'I'm lost. I don't know where I am" (wife of a man with
> dementia).

When his wife was asked if it had taken long for her husband to become familiar with the new arrangement/lay out of the dwelling she replied: 'Oh, a long time, yeah, yeah, a long time, maybe two years' (wife of a man with dementia).

Replacing familiar items in the home also caused some problems as described by one family member: 'we had taken the range out and put the stove in and he was like 'Where's the range?'

you know 'Where's the range?' because he was used to it, he was used to it" (daughter of a man with dementia).

Those with expertise in the area of dementia and those advocating on behalf of people living with dementia and their families understood the importance of familiarity and emphasised the significance of using this principle in designing or adapting dwellings to make them dementia friendly. They also emphasised that this does not need to be at huge expense: 'You can adapt a house to make somebody physically function better but in terms of quality of life it is about having the things like the piano and the photographs and those familiar objects being accessible and close'. This was well illustrated when a man living with dementia interviewed for the study said the following when asked about the design of his kitchen:

> "I built the kitchen myself. I am very, very attached to it … I am more or less
> happy with my kitchen. I have designed it for myself … After 30 years in it, it
> becomes automatic" (man living in his own home with dementia)

7.2.3. Dementia friendly design in different tenure types

All of the people living with dementia and family caregivers participating in the stakeholder interviews were living in their own privately owned homes, all of which were houses. Stakeholders representing local authorities and housing associations stressed the importance of their role in providing social housing for older people, whether through local authority or voluntary housing schemes. They acknowledged that some tenants are likely to have or to develop dementia, but that although they used a Universal Design approach, little consideration had been given to its applicability to dementia in the planning and designing of housing schemes for older people. They stressed the importance of making the guidelines applicable to all tenure types.

7.2.4. Design features to support the Universal Design of dementia friendly dwellings

In the interviews, stakeholders with knowledge of designing buildings for people living with dementia reiterated many of the points covered in Chapter 5 of this report on the external and internal design of the home and it is unnecessary to repeat them here. In addition to familiarity, issues that were thought to be of particular importance in the Universal Design of dwellings for

people living with dementia included legibility, orientation, visual access and personalisation of spaces. It is worth noting that many of these stakeholders had given some thought to design features for people living with dementia in terms of Universal Design and how these features might be of benefit for everyone. An example given by one stakeholder was that 'lowering steps into houses has benefits for parents' whilst the following is another stakeholder's reflections:

"I was thinking about 'what are the types of things that could facilitate somebody with dementia to stay at home longer that everybody could use?', it's things like indoor sensor lights"

Research on buildings in which people with dementia live rarely includes their perspective (Innes et al., 2011). For this present study, a small number of people living with dementia and their family caregivers were interviewed and provided insights into the internal and external design of their homes, so as to give the perspective from someone living with dementia. The biggest issue for one man living with dementia was 'negotiating the stairs' to use the bathroom facilities, especially at night:

"The bathroom is awkward. To use the bathroom you have to go down. That is ok during the day. But at night-time negotiating the stairs" (Man with dementia living in his own home)

A woman living with dementia interviewed for the research talked about the difficulties she experienced finding her way around her home in which she had lived for all her married life and had brought up her children:

"I am very comfortable with that [my bedroom]. However, after that the whole rest of the house I am not very comfortable with (laughs) in the sense that I can go upstairs and downstairs but I wouldn't be at all certain of am I going up that way or down that way. Now because the house is not huge, I find that out. I have the luxury that I only have to work at it. But that makes it hugely important for me to be in my own house" (Woman with dementia living in her own home).

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This led to a discussion about addressing this problem by making the house more open plan:

> "…possibly there are too many doorways and corridors and so if [my mother-in-law] is in the kitchen and she thinks she has to go upstairs she is turning left instead of right and that is all gone unfamiliar whereas before it used to be. [Because of that] she has retreated to living in the kitchen/dining room and the bedroom and nowhere else really … My idea might be possibly if it were more open plan and that you could actually see things. So say downstairs if you knew the kitchen was there and it was all open it might be more suitable for you to recognise things immediately rather than get lost" (Daughter-in-law of person with dementia)

What was striking about the people living with dementia who participated in interviews were the strategies that they adopted to address these difficulties, from simply taking time, to sourcing low cost plug-in motion sensor lights, and designing kitchen furniture to their own specification to help with locating items.

One issue explored in the interviews was stakeholder's views about the inclusion of a retreat area or room in the home where family members and carers might be afforded space and privacy. A Dutch study had shown that this is what family caregivers had expressed a strong desire for (van Hoof and Kort, 2009). In the stakeholder interviews this was broadly welcomed. There were a few participants who expressed reservations about this, but these were the exception. There was also much discussion around the idea of flexible and adaptable spaces in the home that could be used for a variety of functions and some believed that 'we should concentrate on living and life … and even on making places more soulful'. The interviews with people living with dementia revealed the importance to them of having a certain amount of privacy in the home:

> "In fact, the thing I value most is being by myself. Yes, I like it very much … family members come and go and I look forward to them but I'm wondering like 'how long will they be here?' This is because I am to some degree inhibited because they are asking me questions and I may or may not answer them, that sort of thing." (Women with dementia living in her own home)

Outdoor spaces and having natural light in the home were also important and enjoyed by people living with dementia:

> "I can show you my spot (laughter). Last Saturday, Sunday whichever day it was, we have a very small garden in the front and 10 a.m. out in my sun chair, sorry, my armchair, and I was there until 3 o'clock "(Man with dementia living in his own home)

> "Once the sun is there I'll sit … in the sun (Laughs). Once the sun is there I'll talk and sit right here until the sun goes down because it is marvellous. I am always familiar with where the sunny bit is. I follow the sun around automatically, automatically, because the only thing I go to is the sun" (Woman with dementia living in her own home)

One of the implications of this for new dwellings is the positioning of the dwelling to maximize natural light. Many of the stakeholders spoke about the importance of outdoor space and suggested that sensory gardens (tactile/fragrant/colour) can be used to stimulate people living with dementia and encourage them to leave the house and go outside, and that looped paths may help those who have difficulty with way-finding as it provides a route to follow and also so the person will not get lost. Others spoke about designing so as to bring the outside in. For example reference was made to good natural lighting, the clever use of windows and positioning of window sills, especially with the long winters and the weather conditions in Ireland.

7.2.5. Planning ahead for the future

Although the challenge of designing for a progressive condition like dementia was acknowledged, many stakeholders spoke about the need to build in flexibility and adaptability to cater for the individual's changing needs. It was argued widely that there is a need to design homes and incorporate measures such as cables, socket/power points that would allow for future adaptability or installation of aids and equipment if and when the need arises. In other words it was suggest that homes should be "future proofed" and designed to be 'care ready' so that equipment, such as hoists, assistive technologies such as Telecare and community equipment can be readily installed. It was stressed that planners and designers must ensure that the original dwelling design accommodates any future adaption from the outset and that a

dwelling can be simply adapted to meet the changing needs of individual's over time, including people living with dementia, their families and carers.

An ideal approach, according to several stakeholders (allied health professionals and representative organisations of people living with dementia and their families) was to design dwellings so that a member of the household, or a visitor, will be able to live, sleep and bathe entirely on the entrance level for a period of time. A few argued that a shortcoming of Part M of the Building Regulations is that it sets a minimum standard in this regards and only specifies that dwelling should be visitable. There was general agreement that the aspiration should be to design dwellings for people living with dementia to accommodate them to the end of life, not just for those with mild and moderate dementia.

Some family caregivers interviewed had thought about the ageing process and their future dwellings needs. One woman whose husband had recently developed dementia explained that their home originally built with old age in mind was quite adequate for their needs:

> "It's a bungalow … all on the ground … it's only built less than 20 years ago.
> We were thinking ahead … Well, downstairs bedrooms … two bedrooms
> downstairs and that what we use and a shower en-suite and a little sitting room
> then that we can live in, that's it. Everybody admires it and says it's warm."
> (Wife of a man with dementia).

Another interviewee, a daughter of a woman living with dementia, spoke about how when planning to introduce a downstairs bathroom into her mother's house, she reflected on the fact that accommodation might in the future be required on the ground floor:

> "Well, they wanted to change the sitting room into a bathroom and I said 'no
> we build' [an extension] because I [might in the future] want that sitting room
> as a bedroom because we've a two storey so if it's a thing that when she ended
> up there, I've got the sitting room, I've got the kitchen, I've got the bathroom
> and I've got the bedroom and it's all kind of on the one square" (daughter of a
> man with dementia)

One approach proposed was to encourage built environment experts to play a role in getting this message across to people of all ages:

> "the people who have the biggest influence are often architects or builders and if an architect is doing a house extension or refurbishment to a house for a person who is in their 30s or 40s, it can be any age group, is to get the message across to that sector that there's things you can do … and if you do this it could save you a lot later" (Stakeholder)

7.2.6. People with dementia and their family caregivers are not homogenous

Dementia is a complex condition and two different people with the same sub-type of dementia i.e. two men with Alzheimer's disease or two women with Vascular dementia, can experience the Alzheimer disease or Vascular dementia quite differently. Several stakeholders reiterated this point with comments such as 'Each person is different', 'What is perfect for one individual may not be acceptable for another'. The uniqueness of the experience of dementia also applied to people's homes: 'each home is different', 'there is no right answer for every house' and 'one size doesn't always fit all'. It was argued that the Universal Design guidelines for dementia friendly dwellings must acknowledge differences between people and the ways in which they experience dementia and the preferences that they have about the buildings in which they live. In other words, the design needs to be personalised. One implication of this highlighted by stakeholders was that the Universal Design guidelines should not be prescriptive, but should be goal oriented and offer options.

> "Design must be goal orientated which would then concentrate on design quality as opposed to prescriptive guidelines" (Stakeholder interviewee)

> "It is very unique to the individual and you couldn't say that this design is going to be perfect for everybody. All you can say is the more options you can give to people, the more options that there are out there and the more options that people can choose from the better" (Stakeholder interviewee)

Stakeholders themselves made the point that often people living with dementia can have additional sensory impairments, such as hearing or visual, and other co-existing diseases. The

overlap between the needs of people living with dementia and hearing loss and vision impairments, for example, were highlighted. One stakeholder pointed out that visual impairments are frequently under-diagnosed and this will have a big impact. Lighting is utmost importance. Accordingly, guidelines to underpin the design of homes for people living with dementia need to be set in the context of the lighting requirements of older people. Likewise other family members especially older spouse caregivers may also become ill. In this context good home design will also benefit them.

With respect to the dwelling, some stakeholders highlighted that the needs of people with dementia who live alone can be quite different from those living with a family member:

> "There is a difference. We have the carer … who lives with her husband … and we have people with normally early stage dementia that live on their own and there is a whole different set of needs around Telecare, monitoring and all that" (stakeholder).

The following excerpt illustrates this well:

> "Like, he lives on his own like. You know you've got this about locking the door and leaving the key in, you know but he takes the key. Now, I have often gone around in the morning and could be 20 minutes outside that door trying to wake him and I'm like 'Jesus if there's a fire in there' like or something happens like, that we have actually been talking about looking at that door as regards what can we do about this door, you know" (daughter of a man with dementia living alone)

7.2.7. Safety issues and fear of exploitation

Some family caregivers have major concerns about the safety and security of their relatives, especially when they are living in a separate dwelling and the person with dementia was living alone. One main concern was risks of falling. Gaining access to the dwelling could also pose concerns for some as shown above. What is clear is that this family caregiver had not heard of Key Safe,[19] which was recommended by Occupational Therapists participating in the interviews and is readily available. Some interviewees also stressed that safe egress from the building for a

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[19] A key safe is a secure box fitted outside the home where keys can be placed. Each key safe has an individual access code. This can be given to anyone who needs access if the person with dementia is unable to answer the door such as a family member or care worker.

person living with dementia was equally as important as gaining access, and suggested safety features such as monitored smoke alarms for people living with dementia especially those who lived alone, might be a useful safety feature.

Family caregivers and stakeholder organisations drew attention to the need for safety not only within the home, but also what one stakeholder organisation referred to as 'security at the front door'. One architect argued that security and fear of crime were important issues for consideration when designing housing for older people generally. Family caregivers and other stakeholders expressed concern that people living with dementia were being taken advantage of by rogue tradesmen calling to carry out repairs or minor modifications to the home or maintenance of the garden: '… concerns that the family members have about their relative being exploited as for example when tradesmen call to the door and are paid and the person doesn't remembering paying them and they are paid again'. One stakeholder organisation pointed out that this is 'an issue generally speaking that is seen a lot throughout the country'.

According to many key stakeholder organisations, Occupational Therapists have a major role to play in undertaking a risk assessment and providing advice to people living with dementia and their family caregivers about modifications that can be made to their homes. Many stakeholders, especially health care professionals and those advocating on behalf of older people and people living with dementia insisted that a balance between autonomy and risk-taking, needs to be found and argued vehemently for positive risk taking to be a principle underpinning the Universal Design Guidelines for dementia friendly dwellings.

Family caregivers of people living with dementia reported that in undertaking adaptations, builders do not always understand the needs of individuals living with dementia and their families. One informant recounted how the builder was in no way concerned about the safety of her husband with dementia:

> "I remember my husband … during the alterations and he went out the back and …all those boards and everything and he fell out over them and I got on to your man [the builder] and he says 'Tell him to stay in'. That's what he said to me. Yeah … Just went out for something and fell over the pile of rubbish [The builder] had no consideration for him" (wife of a man with dementia)

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The issue highlighted in this narrative is very important given health and safety regulations and the fact that builders are responsible by law for their clients' safety. This same woman described the building work as 'very stressful'.

7.2.8. Involving people living with dementia

Several stakeholders argued that it is critical to involve people living with dementia and their family members in the research and development of guidelines: "I think it would be good to speak to a person with dementia rather than us speaking on behalf of them … it would be remiss of you not to" (Stakeholder). Stakeholders also argued that getting Universal Design for dementia friendly dwellings 'right' meant involving people living with dementia and their families in the process and decisions that were taken about where they live. As one stakeholder put it:

> "It is not just about how the work is undertaken but it is also about how the work is commissioned and the involvement of the person with dementia in how the work is being commissioned and what is being done to where they live"

There was a view that people living with dementia may have to contend with assumptions being made about their capacity to make decisions or express preferences on design or adaptations to their home and it was hoped that the Assisted Decision-making (Capacity) Bill, when enacted, would bring about change in that regard.

One architect with experience of designing dwellings for older people and people living with dementia argued that it was imperative to find out what people living with dementia actually need and how they experience living in dwellings that have been designed for dementia and those that have not. Others spoke about the general lack of awareness about the possibility of getting feedback about the design from the perspective of people living with dementia. Although it was acknowledged that it was not always easy to get feedback from people living with dementia, especially those with severe dementia, some stakeholders believed that it would be valuable to carry out a post-occupancy evaluation of buildings designed or retrofitted for people living with dementia, their families and carers. As one stakeholder argued: 'It is also about generating evidence so if you do retrofit a house or you do design a house for somebody with dementia there is evidence to show that it does have an impact'. Another approach

suggested was to establish what works for people living with dementia in residential care settings and apply this to communities and homes, where appropriate.

7.2.9. Sustainability and energy efficiency in people's homes

As Chapter 1 mentioned there is an inextricable link between sustainability and Universal Design. Whilst stakeholders spoke about building dwellings so that they are adaptable and flexible over the lifetime of the dwelling, people living with dementia and family caregivers didn't explicitly mention sustainability. They were, however, acutely aware of the day-to-day costs of fuel and having the heating on.

> "The heating system in my house works because the person who is there likes it hot and I don't like it on. I feel it is very wasteful anyway. I, when I am more or less on my own, reduce it. This is the old system of saving (Women living at home with dementia)

This could be the cause of great concern for family members, who emphasised the importance of keeping the house warm:

> "He reckons he has no money. Even a friend of mine across the road, she texted me and she said to me your dad's sitting in the dark and I had to go around and turn on the light. I said to him 'Da, there's no fire on' and he'll give me the excuse, 'I'm only up' … he's like 'If I don't light the fire until 2 o'clock I'm saving', you know" (daughter of a man with dementia).

> Even today, the briquette fellow came and he's 'How many bails of briquettes did I get?' '10' 'How much is that?' '€40' … now the briquette fellow actually came to me and said 'Your father cancelled' and I say 'You keep coming until I tell you' (daughter of a man with dementia).

Energy inefficient dwellings leaves people living with dementia, on the one hand, concerned about the cost of heating their home and their family members, on the other, greatly worried that their relatives might be freezing in a cold house. This clearly has an impact on the day-to-day lives of people living with dementia and their family caregivers and highlights the added value of making dwellings for people with dementia that are energy efficient and properly insulated. It was an issue that was raised by other stakeholders as well:

"There have been changes to the household benefits package and people's energy units are being cut and this is having a significant impact on people's ability to meet those energy bills and because older people don't have the opportunity to generate income the same way that people of a younger age … there is a fear around not having enough money to pay the bills … so there is an issue around that but something like sensor lights could even be energy efficient".

7.2.10. Costs and cost savings

One issue raised by stakeholders was the potential cost savings that would flow from improving the dwellings of people living with dementia. It was mentioned that investing in the design/retrofit of the home could potentially rule out or delay the need for admissions to hospitals and long-stay residential care and as one stakeholder put it: 'if you think of design aspects at a very early stage it is an awful lot cheaper than retrofitting afterwards'. The different costs highlighted by stakeholders that were associated with designing and retrofitting dwellings for people living with dementia ranged from low cost, moderate to high cost. Stakeholders stressed the importance of indicating what level of cost pertained to different aspect of Universal Design features for dementia friendly dwellings. However, the amount of funding available and consideration of the costs must not it was argued, be the starting point. Rather, supporting people living with dementia to remain living independently in the present environment was argued to be a key goal.

Several stakeholders argued that thinking about designing for people living with dementia and their families and carers at a very early stage of the design for a new build or extension/refurbishment of an existing dwelling is a lot cheaper than retrofitting afterwards. Nevertheless, questions were raised about the cost of adapting a home and who would bear this cost: 'where are people going to get the money to adapt their home? It comes back to the cost constraints'. With both of these in mind, several stakeholders emphasised the importance of changes that are cheap and easy to make, and because of the significance of familiarity for people living with dementia, cautioned against making major changes, which might not only be expensive to implement but also because major change could interfere with a person living with dementia's ability to live independently. It was argued that Universal Design for dementia friendly dwellings does not have to be expensive and examples of cheap or no cost solutions

offered included introducing visual cues, clocks and calendars, and a simple timer. It is worth noting Stephen Judd's point that '… providing the best physical environment for people with dementia is not a question of money or luck, but of good, thoughtful, person-centred design' (Judd, 1998).

7.2.11. Funding for adaptations

Money is an issue when major adaptations are needed, but arranging funding for adaptations is far from straightforward (Hemingway, 2011). In Ireland people living with dementia, their families and carers may rely on their own resources and pay out of pocket costs for adaptations and for temporary accommodation if needed, as had been done by one family participating in the stakeholder interviews. Alternatively an application can be made for financial assistance through the Housing Adaptation Grant (HAG). Two families participating in the stakeholder interviews had taken this approach when adapting their homes. The Grant is means-tested and involves an assessment – by an occupational therapist. Stakeholders highlighted the barriers people living with dementia and their families experience in applying for this grant, which included the limited resources made available by local authorities and the existence of long waiting lists. According to the stakeholders, the recent cutbacks in public expenditure have impacted heavily on the HAG and have exacerbated the already long waiting lists. There was considerable discussion about the geographical inequities that exist due to the variations between local authorities regarding the budgets available and local demand.

> "Just with the grants … there is a huge issue around the house adaptation grants and availability of funding to do adaptations to your home. They cut it by 35 or 40%" (Stakeholder 1)

> "Well, it depends on what council you are in. Some are now experiencing 80% cuts so it depends on what their budget is and the number of people in the area but it is between 35% and anything up to 80% cuts and they're suspended for the last two years anyway over 20 of the 31 councils… You get on a waiting list. And the waiting list you could actually be on it for four years in some situations" (Stakeholder 1)

Stakeholder organisations reported that only applicants classed as 'top priority' tended to be successful in getting the grant. Stakeholders were of the view that people living with dementia were often excluded from accessing the HAG, since those needing adaptations for physical

impairments were prioritised. It was reported that unless they had a serious physical disability, people living with dementia applying for the grant were generally refused. Home owners thus may be discouraged from applying for the grant.

There were concerns expressed by some stakeholders that local authorities, in their attempts to keep the costs of housing adaptation grants low, were undermining the quality of life of people living with dementia and their family caregivers, as the following extract illustrates:

> "We had a case … where a husband was caring for his wife who has dementia … It's a small house they're in and they have a small sitting room and a kitchen and a small bathroom downstairs and they were going to have the bathroom but the OT came in and she said actually 'what are you going to do for a bedroom? You need a bedroom' …. First he put the application for a bathroom and then he added it in for a bedroom but the people who were looking at it from the council said 'No, no, convert your sitting room into a bedroom' and he said 'where would we sit?' and they said 'Well you don't need somewhere to sit. You can sit in the bedroom with a couch'. So it's just I suppose the thinking of, they're not thinking of this man as a carer will have no sitting room if he converts it to a bedroom" (stakeholder).

In a discussion with stakeholders from one local authority it became apparent that housing officers have little knowledge of dementia but stated that they would welcome an opportunity to learn more about dementia, how it affects those living with the illness, their families and carers and their environment, and how Universal Design could be used to support people with dementia living in their own homes. They were open to the idea of exploring ways in which the HAG could be used to fund adaptations that would improve the lives of people with dementia. Public expenditure cutbacks have also had implications for the social housing sector, as there has been a decline in financial support for Capital Assistance Scheme.

7.2.12. Universal Design for Dementia Friendly Dwellings undermined when community care/support services are lacking

People living with dementia participating in interviews stressed the importance of remaining in their own homes and this was supported by family caregivers and other stakeholders:

"if appropriate supports can be provided into the home there is no reason why you should move the person out of the home because that is taking them out of the place where they want to be where their family wants them to be, so anything that can be done to encourage that is obviously the direction we should be going"

It was widely acknowledged by stakeholders that government policy is to help people with dementia to remain living at home for as long as possible. However, family caregivers especially those who had experience of caring for relatives living with severe dementia, commented on the difficulties in getting home care. They highlighted the importance of having supports in place to assist with the care of people living with dementia and how the lack of such supports undermined efforts made to design dwellings to be dementia friendly.

" … I think … the council are there 'sure grand go ahead and build it' but that is only half the answer. If you don't have the support coming into the house, you can have a lovely downstairs bathroom and bed, but if you haven't got someone to help take the person with dementia out of the bed and into the bathroom, that it is only you, you might as well not have that" (stakeholder).

A comment like this reminds us of the type of possible solutions (such as layout, ceiling hoists or training) which might make the caring role easier both for informal and formal carers.

Several stakeholders also raised this point, arguing that the physical environment can be undermined if formal care is not adequate to support the unique needs and abilities of people living with dementia and their family caregivers: "At the moment there are challenges in providing the appropriate quality and quantity of home supports" (Stakeholder).

7.2.13. Universal Design Guidelines for dementia friendly dwellings

With some exception, there was a broad welcome for the development of the national Universal Design Guidelines for dementia friendly dwellings, the development of which were considered to be timely and much needed. However, stakeholders made several suggestions regarding the guidelines and also expressed some concerns about them. It became apparent in conducting the one-to-one stakeholder interviews that a plethora of standards and guidelines are already in existence, though not specifically with regard to designing dwellings for people living with dementia or from a Universal Design approach.

A concern was expressed by some stakeholders that the new guidance document would become lost in a sea of guidelines. To avoid this, it was argued that the new guidelines need to be practical and easy to use and to 'definitely have the guidance [with] an executive summary or here are the top ten things' to get the message across. It was argued by many that the design guidelines should be non-prescriptive and rather 'give you an understanding of dementia and make you think about what needs to be done'. To support this it was suggested by many that the guidelines need to offer users choices between options and plenty of examples of what can be done.

One stakeholder suggested a 'focus even on the visual side, pictures so that people can capture that [key messages] quickly'. Another stakeholder who was concerned about the volume of information contained in guidelines suggested developing an online version of the Universal Design guidelines for dementia friendly dwellings: 'the capability of having something online gives you more scope to find your way through and if they want to know more they can dig deeper and deeper and if they don't they don't have to'. Stakeholders also pointed out that if the guidelines are to be useful for both new build and existing dwellings, it would be important to address the different levels of adaptations that can be carried out in both new and existing dwellings.

7.3. Stakeholder workshops

Two stakeholder workshops were held during 2013, both of which were held at the National Disability Authority, Dublin (see Appendix 2 for attendees). The first took place on June 21st 2013 and the second in late October 2013. The primary aim of these workshops was to engage once again with stakeholders and to keep them abreast with all research findings and project progress.

Regarding the first workshop, some 39 individuals (representing 25 stakeholder organizations) attended. They comprised architects, planners, landscape architects, social workers, occupational therapists, physiotherapists, researchers and representatives of older people organisations, people with disabilities and people living with dementia. The primary aim of this first workshop was to present preliminary research findings and to discuss with key Stakeholders the main issues that arise in designing and retrofitting dwellings for people living with dementia, their families and carers from a Universal Design approach. A

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secondary aim was to learn from the expertise of the diverse group and share experiences through the use of design exercises which presented the stakeholders with four typical scenarios involving people living with dementia (See Appendix 3-5). The feedback from the workshop highlighted a number of key issues, which have been grouped under the following themes: Awareness and understanding; Support for family members and carers; User engagement; Familiarity; Design Interventions; Assistive technology; Adaptability and flexibility; Cost; Sustainability; Onsite implementation; and Building management. The feedback from the workshop has been used to inform the draft design guidelines titled 'Universal Design Guidance for Dementia Friendly Dwellings.

As mentioned, a second workshop was held on 29 October 2013, the aim of which was to present an overview of the draft design guidelines to the key stakeholders and obtain feedback from them with a view to developing a final set of design guidelines. A wide range of stakeholders, including many of those who had participated in the first workshop attended the second workshop.

The workshop provided an opportunity for Dermod Slevin, a man with dementia and a member of the National Working Group of Persons with Dementia, to give a personal account to the stakeholders of what it is like to live in his own house. This man during an interview at the workshop, very ably described some of the challenges he faces and the strategies he adopts to overcome them. This fitted in well with the main theme of the workshop which was to bring the person living with dementia and their family caregivers centre stage, which was a marked change from the earlier part of the first workshop when many of the stakeholders focused exclusively on the design of the buildings presented to them with the residents considered as an afterthought.

To summarise, both workshops were very well attended and generated much interest and a lot of discussion about the Universal Design approach for Dementia Friendly Dwellings. The experience of working with people from other professional backgrounds was reported by several participants to be informative and educational. The first workshop placed a lot of emphasis on the Universal Design principles for making dwellings dementia friendly. Participants welcomed and broadly accepted these principles.

7.4. CONCLUSIONS

A number of concluding remarks can be drawn from these stakeholder interviews. First there is a need to raise professional and public awareness about dementia and Universal Design for dementia friendly dwellings. Following on from this, there is a need to up-skill all of those whose work has relevance for making dwellings dementia friendly from a Universal Design approach – from policy-makers, health care professionals, planners, designers right through to builders and tradesmen. Approaches to awareness raising, education and training on Universal Design for Dementia Friendly dwellings include the introduction of Universal Design for Dementia Friendly Dwellings into Universal Design modules in undergraduate/postgraduate courses; the development of an interdisciplinary Continuing Professional Development (CPD) course on UD for Dementia Friendly Dwellings; practitioner meetings (e.g. Housing officers with the local authorities, architects, engineers and health service professionals); awareness raising, education and training of builders and tradesmen. Built environment experts should be encouraged to think ahead and incorporate flexibility and adaptability into the planning, design and retrofit of dwellings so that they can better accommodate people who develop dementia, the majority of whom are older people and may have other disabilities and/or coexisting morbidities.

Familiarity is critical when designing new dwellings but especially when retrofitting dwellings for people living with dementia. People living with dementia are much more relaxed and confident if the environment around them is familiar to them. When designing dwellings for people living with dementia, it is important to see past their diagnosis and gain an understanding of the person their likes and dislikes, their fears and desires and those of their family members' and carers'. More attention needs to be given to enabling designs (e.g. adequate light levels, contrast and colours, bringing the natural light in) and assistive technologies. Listening to what people living with dementia, their families and carers have to say can help us re-imagine the design of the home environment.

There are economic, social, and quality of life costs of not designing dwellings for dementia from a Universal Design approach. Listening to stakeholders and involving people living with dementia and their family members can help everyone involved in this work to better understand how people living with dementia their families and carers experience living/working in the home, to broaden the debate and help everyone involved consider their role individually and collectively in promoting Universal Design for dementia friendly dwellings.

7.5. Key Recommendations

- In terms of practice, the first key recommendation is the need for all personnel working in areas which might directly or indirectly bring them into contact with people living with dementia and their families, to be better educated about dementia and about how this condition affects the lives of all those diagnosed. We found several examples of the absence of awareness and understanding of dementia amongst some local authority personnel, city council, built environment staff and even amongst some health service professionals who in the context of their remit to assess clients for home adaptations tended to be thinking in terms of older people with a physical disability rather than those with a cognitive impairment.

- As stated above, there is a need for education and training of relevant local authority staff, design professionals and allied health staff about dementia and designing for people living with dementia, drawing on Universal Design principles. There is a need to up-skill building contractors and tradesmen about some of the key symptoms of dementia and about ways to best communicate with people living with dementia when work is being carried out to a house still occupied by a person with dementia. For in the absence of appropriate communication, the person living with dementia may be hugely destabilised by having unfamiliar faces/intruders in their home. In general, dementia training especially training on design should be extended into architectural, built environment professionals health and allied health professional undergraduate and postgraduate courses and into continued professional educational courses.

- In terms of policy development we would recommend that the Universal Design approach for Dementia Friendly Dwellings should be incorporated into future iterations of the relevant national housing strategies, policies, regulations and guidelines and for a more inter-sectoral approach to be taken to dementia care. For example, the national housing strategy for people with a disability, the housing policy framework, and documents such as delivering homes sustaining communities, or Part M (2010) of the technical guidance documents must where relevant, reflect some of the key findings from this research. In the light of the Irish government's policy commitment to community care for people living with dementia, the National Dementia Strategy needs to reflect ways by which government policy can

realistically support older people living with dementia to continue living at home despite their disability.

- We found that there is a lack of information available to people and their family members affected by dementia, with respect to their eligibility for certain home adaptation services and an absence of guidance available to them about whom to consult regarding their specific housing needs. Our research showed that Housing Adaptation Grants (HAG) have been seriously cut in recent recessionary times with only "top priority" cases now awarded these grants. In this context, we found that it was the belief of many stakeholders, including family caregivers and their representative organisation that physical disability is prioritised over cognitive impairment and that unless a person with dementia had a physical disability accompanying the cognitive impairment, they were generally refused such grants. If this is the case, we believe that people living with dementia should be assessed on an equal merit rating, compared with people with a physical disability. We would recommend that personnel administering these grants be more cognizant of the complex needs of people living with dementia and their families and carers in the home and of the equally high priority status these people have.

Chapter 8: Conclusions

8.1. Introduction

This research was commissioned by the Centre for Excellence in Universal Design at the National Disability Authority. Its aim was to help generate national guidelines for the Universal Design of new dwellings and the retrofit of existing dwellings for people living with dementia, their families and carers. At all stages in the course of conducting this study, Universal Design principles remained of critical importance. Likewise the research aimed to build on and extend the former work of Centre for Excellence in Universal Design at the National Disability Authority with particular reference to their 2012 publication titled "Building for Everyone: A Universal Design Approach" and their 2014 draft guidelines, titled "Universal Design Guidelines for Homes in Ireland". This chapter draws the report to a conclusion and makes recommendations, which will be returned to, in the actual design guidelines drawn up in a separate document.

Chapter one has provided the context and the rationale for this study. In that chapter it was shown that there are currently about 48,000 people living with dementia in Ireland and that because of population ageing, this number is likely to increase significantly over future years. It was argued that government policy in Ireland is committed to community care and that most people diagnosed with dementia in Ireland, remain living in their own homes and are supported by family members who play a pivotal role in caring for their relatives with dementia, and to a lesser extent by formal carers and health care professionals, by voluntary services and by local

authority supports where relevant and when available. Yet ironically there are no guidelines available in Ireland to help government departments, local authority personnel, built environmental professionals and architects design new or retrofit pre-existing dwellings for people who live in their own homes and who later develop a dementia. This chapter also introduced the reader to the concept of the Universal Design approach and showed how the United Nations Convention on the Rights of Persons with Disabilities broadly speaking embraces the principles of Universal Design. Chapter one also showed how Universal Design principles align well with environmental sustainability. This chapter also outlined the methodology which was used in this research, namely an extensive literature review and critique, stakeholder interviews, stakeholder workshops and case studies. The chapter concluded with an overview of the structure of this report.

Chapter two then progressed to a discussion of the relevant theories and models that have influenced the way in which dementia is conceptualized in contemporary times and how dementia is defined in this research study. The chapter then advanced to a discussion of the early literature on the built and social environment in the context of dementia care. It described the "Person-Environment" and "Person-Activity-Environment" Models and the International Classification of Functioning (ICF) model. It showed how the ICF model provides a useful framework for a Universal Design approach to dementia friendly dwellings since it places human activity (including of people living with dementia, their families and carers) and social participation at the centre-stage. It was argued that the ICF model connects the individual to the environment and demonstrates how health and well-being cannot be understood exclusively at a body function or individual level. It was shown that the ICF model stresses the importance of social participation and acknowledges the role of the environment in creating disability. The chapter argued that the ICF model has much application to dementia, where all too often, the individual's entire behavior can be seen through the dementia and not through other equally important domains like the environment, activity levels, personality, health status, caregivers' behavior and social participation.

Chapter three advanced into a more in-depth discussion of the topic of the principles, goals and guidelines of Universal Design. The discussion in this chapter then set the scene for a review of some of the key contributions made by international experts such as Lawton, Marshall and Calkins who have written about best practice and design for dementia from a Universal Design approach. The point was made that by far the bulk of these writings pertain to

design for long-term residential care and not design for people living with dementia who wish to remain in their own homes and their families and carers. Efforts were made in this chapter to examine areas where these experts' works overlapped and where their thinking and writings converged or diverged with Universal Design principles and goals. Given the researchers' remit to examine from a Universal Design approach, commitment to developing design guidelines for home dwellings for people living with dementia, some revision/amendments were made to Marshall's design features to enable them to have application for home dwellings. The amendments were most notably made in the area of: (i) the recognition of the need for the ethical use of assistive technology, (ii) an acknowledgement that design goals should promote autonomy and choice, and that (iii) design should recognize the important role of family members and caregivers. These revised design goals are listed in Chapter three and will be revisited in the design guidelines, which will accompany this report.

Chapter four then reviewed the literature, which deals with the topic of the lived/subjective experience of dementia from the perspective of people living with dementia and their families and found that there is a dearth of literature on formal carers and the subjective experiences of the dwellings in the context of caring for people living with dementia. As is the case with most of this literature, the majority of articles, books and reports drawn on, were shown to pertain to people with dementia living in long stay care facilities as opposed to those living in their own homes. This chapter argued that in order to create dementia-friendly environments for people living with dementia, their families and carers, it is first important to have a good understanding of the disability of dementia, and of how dementia can affect peoples' memory, cognitive functioning, communication patterns and behavior. It was shown that many people living with dementia may also have other age-related health problems, which may exacerbate the dementia and interfere with their ability to negotiate their home environment. Some of the common safety concerns that carers have when attempting to provide home care were discussed in this chapter. These included falls, the propensity of the individual to get lost both inside and also outside the home, their being at risk of burning, scalding themselves or engaging in other potentially dangerous behavior. A key argument marshalled in this chapter is that it is inadvisable to over-protect people living with dementia and that whilst their safety and security should always be of paramount importance, positive risk-taking should also be a guiding principle underpinning the Universal Design of dementia friendly dwellings.

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Chapter five provided a very comprehensive review of the literature on the topic of the design of buildings, and adaptation/retrofitting of dwellings for people living with dementia, their families and carers. Keeping the principals of Universal Design in mind, literature findings in this chapter were as far as possible presented using headings and sub-headings drawn from the Centre for Excellence in Universal Design at the National Disability Authority, 2012 document *Buildings for Everyone: A Universal Design Approach*. Based on the literature, this chapter provided considerable detail about home location and approach, about entering, exiting and moving about the home, about spaces for living, interior design, and internal services and about elements within the home. This chapter also looked at the way in which sustainable design has much relevance for Universal Design for dementia friendly dwellings.

Chapter six identified and described three case studies reflecting best practice in designing for dementia in three "housing with care" schemes. The schemes have been purposefully built to cater for the complex and unique needs of people living with dementia. All were drawn from the island of Ireland where people living with dementia are currently in residence. A fourth case study was drawn from the Netherlands where the house is a pilot scheme and model demonstration site with no occupants.   The case studies demonstrate the way in which design features such as lighting, floor finish, colour contrast, signage, items of memorabilia (such as memory boxes) and assistive technology can be used to support people with dementia. The chapter illustrates the ways in which some of these design features can be creatively used to compensate for the disability of dementia. In this chapter, the layout and design of each of these housing types/buildings were described in detail and the strengths and weaknesses of each evaluated.

Chapter seven reported key findings from 39 stakeholder interviews. These interviews conducted were mainly one-to-one but a few were undertaken in group format. They were undertaken with representative voluntary organisations of older people; people living with disabilities and people living with dementia; with government departments, local authorities, housing providers, the HSE, allied health professionals, architects, landscape gardeners, house builders, engineers and quantity surveyors. Most importantly and in keeping with Universal Design principles, direct user involvement was considered critical to the research and interviews were also conducted with people who have dementia themselves and their family members and carers.

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The key themes emerging from those interviews were: (i) the need for improvements in awareness and understanding of dementia; (ii) the importance of familiarity (environmental) in the home; (iii) importance of dementia-friendly design in different tenures; (iv) the relevance of design features which support Universal Design for dementia friendly dwellings; (v) the salience of planning ahead; (vi) the uniqueness of every person living with dementia and his/her family members; (vi) safety; (vii) the importance of user engagement and involvement; (viii) sustainability; (ix) costs; (x) funding; and (xi) the need for adequate statutory, voluntary and local authority support services. This chapter also reported findings from both of the workshops conducted during 2013. A key argument marshalled in chapter seven was that significant economic, social and emotional costs can be incurred by people living with dementia, their family members and carers, when dwellings are not adapted from a Universal Design approach. Through the rich and insightful narrative, the chapter demonstrated the importance of listening to stakeholders' accounts, particularly the views of people living with dementia, their family members and carers. After all these are the people most significantly affected by any retrofitting work undertaken or by any new design features that are introduced.

8.2. Discussion

Based on this research, we would argue that the Universal Design approach supports and fosters the creation of dementia friendly home environments. Our argument is based on the premise that the seven principles contained in Universal Design namely: (i) equitable use; (ii) flexibility in use; (iii) simple and intuitive; (iv) perceptible information; (v) tolerance for error; (vi) low physical effort; and (vii) size and space for approach; are each compatible with the goals of best practice in designing dwellings for people living with dementia. Likewise broadly speaking, the four Universal Design guidelines, as shown in Section 3.3.4, namely, a building that is: (i) integrated into neighbourhood; (ii) easy to approach, enter and move about; (iii) easy to understand, use and manage; and (iv) flexible cost effective, safe and adaptable over time; supports in our view the creation of a Universal Design approach to dementia friendly home dwellings

It has also been shown that Universal Design is not a one-size-fits-all approach, but instead, creates a higher more inclusive baseline, from which specialised care can operate (Sanford, 2012). This is critical in applying the Universal Design approach to the design of dementia friendly dwellings, as it facilitates an accessible, usable, and easy to understand environment for

a wide range of people (regardless of ages, sizes, ability or disability) who may live and/or undertake care work in the dwelling. It is also inclusive and accommodates different requirements of the resident, and may reduce the need for specialised design while providing flexibility to provide specialised design where required.

In addition, the Universal Design approach requires an iterative user-centered design process based on stakeholder participation. The way in which the Centre for Excellence in Universal Design at the National Disability Authority conceptualizes and promotes Universal Design aligns well with contemporary thinking about the need to include the voices of people living with dementia in service planning and "to facilitate their involvement in policy formulation and implementation", a goal of advocacy groups like the Alzheimer Society of Ireland and the Dementia Services Information and Development Centre, St James's Hospital and a recommendation highlighted in a recent government commissioned report on dementia in Ireland (Cahill et al 2012 p.126). In short Universal Design principles are consistent with current thinking around dementia care, which seeks to promote personhood; maintain a person's agency and consider that person in a holistic manner as a biological, a psychological, and a social entity.

In support of this iterative user-centred Universal Design process and the desire to be truly inclusive of all key stakeholders, this study set out to engage in-depth with a diverse range of stakeholders identified from a large number of governmental and non-governmental organisations throughout different stages in the research process. As shown such engagement was achieved through a series of one-to-one interviews, group interviews, stakeholder workshops and site visits undertaken to a select number of housing with care schemes with specific dementia friendly features. In particular and as far as possible, we attempted to keep the person living with dementia and their families at the centre by conducting whenever possible one to one interviews with them and with their family members and carers. As shown in the previous chapter, their insights have proven to be invaluable in terms of informing this research.

Critical issues highlighted include the vulnerability of people living with dementia and the challenge for design experts of sometimes having to simultaneously design for two groups of people with very different needs (in one case physical, in the other cognitive). Other important issues for those with dementia who want to remain in their own homes include the need for

privacy, access to safe outdoor areas, the importance of being safely able to negotiate staircases, way finding and the practicalities of coping with home construction work, taking place when they as the occupants continue to reside at home. This process of user engagement significantly informed and shaped the direction of the research and also shaped our findings. It resulted in grounded, practical recommendations which not only provide the evidence base for the design guidelines but also prompt a range of broader recommendations for the Universal Design of dementia friendly dwellings. Although several key findings have emerged based on data collected at different stages of this research study, the four core and most recurring themes were summarised and will now be discussed.

8.2.1. Awareness and understanding

Many design professionals and local authority staff lack knowledge and understanding of dementia (see Section 7.2.1.), its signs and symptoms and the appropriate design measures that can be used towards creating a Universal Design approach to dementia friendly environments. Accounts provided by stakeholders (See Chapter 7) highlight the need for education and training in this area. Several of these participants suggested including the topic of dementia into relevant Universal Design undergraduate and postgraduate courses and into continuing professional development. There is also a need to raise professional and public awareness about dementia and the salience of Universal Design for dementia friendly dwellings. There is a need to up-skill all of those whose work has relevance for making dwellings dementia friendly – from policy-makers, planners, designers right through to builders and tradesmen. Approaches to awareness raising, education and training on Universal Design for Dementia Friendly homes include the introduction of Universal Design for Dementia Friendly Dwellings into Universal Design modules in undergraduate/postgraduate courses; the development of interdisciplinary Continuing Professional Development (CPD) courses on Universal Design for Dementia Friendly Dwellings; practitioner meetings, e.g. Housing officers of local authority staff and awareness raising, education and training of builders and tradesmen. Government and local authority personnel and built environment experts should be encouraged to think ahead and incorporate flexibility and adaptability into the planning, designing and retrofitting of dwellings so that they can better accommodate people who develop dementia, the majority of whom are older people and may have other disabilities and/or coexisting morbidities.

8.2.2. Support for families and carers

Caring for someone living with dementia is often hard physical work. For informal carers, caring duties can extend around the clock and apart from the tending tasks involved, dementia care can result in the need for monitoring the person, ensuring he/she remains safe and that boredom is allayed and the person is kept occupied. It is well known that family caregivers in Ireland provide the main bulk of care for people living with dementia in the home and receive very limited support from statutory and voluntary services. Often these carers are older themselves; they may not enjoy good health and are often hesitant about placing demands on their adult children whom they believe have their own responsibilities and obligations. The stakeholder interviews revealed the dilemmas some people experienced trying to negotiate their way around their own homes in the absence of design solutions. They also highlighted the difficulties encountered by some when home retrofitting or adaptations were made but when the person living with dementia was not adequately consulted or was unable to adapt to the new unfamiliar lay out. The absence of support offered to families to enable them continue to provide home care was also highlighted and the point was made that design solutions could be completely undermined if families were not offered appropriate support to enable them make optimal use of the new home lay out.

It was acknowledged by many stakeholders that no two people with dementia (even two people with the same type of dementia such as Alzheimer's disease or Vascular Dementia) are alike. The transition of people living with dementia from home into long-term care is often precipitated by safety concerns, by caregiver burnout, by challenging behaviours and by the inability of a family member to continue to provide adequate care in the home. Since one of the main goals of Universal Design centres on designing for all people regardless of age, size, ability or disability, then this approach certainly supports the family caregiver in the caring role but needs to be augmented when relevant by appropriate home and community care supports. A Universal Design approach is similarly supportive of informal carers providing care to people living with dementia in the home. In some cases, the time will come, no matter how well adapted the environment is, that the person with dementia will need 24 hour assistance. Accordingly, there are times when a Universally Designed dementia friendly environment, while very important, will not support a person with dementia indefinitely to live well at home.

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8.2.3. User engagement and understanding people's needs

The importance of involving the person living with dementia, family members and carers in the design process and of fully understanding their individual needs and preferences emerged as critical to good practice in this research. In fact during the first workshop, held in The Centre for Excellence in Universal Design at the National Disability Authority, some vignettes were administered to the stakeholders, who were asked to identify design solutions that might make dwellings less problematic for people living with dementia and/or to their families. When this task was first attempted, none of the stakeholders reflected on the importance of initially talking to the individual with dementia and their family members. Later that same morning when educational materials on best practice and Universal Design for dementia were imparted and when the question of how they might address the problems was asked, most of the five groups claimed they would change their approach. Indeed most identified how they would first, if possible, talk with the person living with dementia and family members in order to learn their wishes and preferences. This approach as stated earlier is well aligned with both Universal Design approaches and best practice in dementia care as identified by the Alzheimer Society of Ireland and the Dementia Services Information and Development Centre.

8.2.4. Familiarity

The importance of familiarity both environmental and behavioural was highlighted in both the literature and in several of the stakeholder interviews as shown in the previous chapter. Familiarity is a crucial dementia-friendly design issue (See Section 3.3.4.) which operates at a number of levels and is largely predicated on the fact that people living with dementia often retain good long term memories while their short term memory slowly becomes seriously impaired. New learning may also be a challenge for a person living with dementia because of the disability. Therefore maintaining a person in his/her own home and in that person's own locale (neighbourhood) with its familiar surroundings is always recommended. However, if dwelling adaptations or a building extension is required, this can introduce new and unfamiliar features and may thus cause some further disorientation, confusion and distress. The rich narrative in Chapter 7 reminded the reader vividly yet poignantly of some of the dilemmas and difficulties experienced by people living with dementia, their families and carers when they are required to come to terms with new arrangements due to home modifications.

The use of contemporary design features, which may be accessible and usable to the general population, may require some level of rationalisation and learning for a first time user and this may cause issues for the person living with dementia. We have highlighted four key issues since they were recurrent themes throughout most of the stakeholder interviews, however, as shown in the previous chapter there were several other themes which also emerged and which have been fully described. This final section of this chapter now attempts to draw together the key practice, policy and research recommendations that appear in previous chapters.

8.3. Recommendations

Findings from this research have implications for practice, policy and future research and the final part of this chapter will now address these areas respectively.

8.3.1. Practice

In terms of practice, a key recommendation arising from the research is the need for all personnel working in areas which might directly or indirectly bring them into contact with people living with dementia and their families, to be better educated about dementia and about how this condition affects the lives of all those diagnosed. We found several examples of the absence of awareness and understanding of dementia amongst some local authority personnel, city council staff, built environmental professionals and engineers and even amongst some health service professionals who in the context of their remit to assess clients for home adaptations tended to think more in terms of older people with physical disability rather than those with a cognitive impairment.

As stated earlier, there is a need for better education and training of staff in relevant government departments and staff in all local authorities. There is a need for the education and training of design professionals and allied health staff about dementia and designing for people living with dementia, drawing on Universal Design principles. There is a need to up-skill building contractors and tradesmen about some of the key symptoms of dementia and about ways to best communicate with people living with dementia, their families and carers since when work is being carried out to a house still occupied, that person may be hugely destabilised[20] by having unfamiliar faces/ intruders in their home. In general dementia training especially training on design should be extended into architectural, health, built environment and allied health

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[20] Such will not affect all people living with dementia.

professional under-graduate and post-graduate courses and into continued professional educational courses.

We found a lack of information available to people affected by dementia about their eligibility for certain home adaptation services and an absence of guidance available to them about whom to consult regarding their specific housing needs. Our research showed that Housing Adaptation Grants have been seriously cut in recent recessionary times and it would seem that only "top priority" cases today being awarded these grants. In this context, it appears that physical disability is prioritised over cognitive impairment and that unless a person living with dementia had a physical disability accompanying the cognitive impairment, they are generally refused such grants. We believe that these people and their families shoulder a massive burden that the state does not pay for and therefore the family should be included in assessment. Most importantly the assessment of people living with dementia should be on an equal merit rating with people with physical disability. We would recommend that personnel administering these grants be more cognizant of the complex needs of people with dementia living at home, their family members and carers and given a high priority status.

Furthermore, our research suggested that a considerable time delay existed between when families first seek out advice particularly for assistive technology and when such interventions were finally introduced. Many of the families we interviewed appeared to be very resourceful in devising their own solutions to the problems they encountered in their homes.   Others could have been helped had they had the expertise of built environmental professionals and/or health service professionals who might show them ways of using signage and labelling effectively. Solutions could have been made easier and more beneficial perhaps if experts were consulted.   In the context of this research, the two main categories of AT found were (i) Telecare (with low, medium and high levels of assistive technology) and (ii) Smart Home Technologies. There is a need for a lot more information about technologies to be made available to the public. Information could be posted on relevant websites or information booklets could be compiled by organizations like the Alzheimer Society of Ireland or Carer Support groups in conjunction with government departments, local authorities and built environmental professionals.

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We found that a high proportion of Irish housing stock is over 30 years old and this coupled with current recessionary times (where few buildings are being constructed) means that

adapting pre-existing housing stock will most likely in the context of dementia be a priority. Therefore the Universal Design guidelines to be developed must be usable in this context and must be perceived as being applicable to existing dwellings. The challenge in the context of dementia is making home adaptations completed in such a way that the general layout of the environment remains as familiar as possible to the individual. Regarding the adaptation of existing homes, family members need to be advised of the implications that the work may have on their relative with dementia in terms of noise, disruption and unfamiliar faces inside their private homes.

An issue that arose over and over again at both workshops and during interviews was the costs involved in making appropriate home adaptations to help people compensate for the disability of dementia. In certain situations, financial costs may be quite excessive, particularly where building extensions are required and as shown in this report government support by way of grants to help defray building and other remedial costs are limited and seldom available to people living with dementia. Families need to be made aware of this. They need to be very clear about when is the optimal time for adaptations to be introduced in order for them to be cost effective. This issue of timing is so important since, if significant time lag occurs between assessment and home adaptation, design interventions may come too late and may be ineffective. As shown earlier, cost effectiveness is an integral component of Universal Design principles. Ideally all new dwellings should be fitted out with equipment and technology such as power points strategically located for future use, cooker switch off devices, flood detectors, night lamps which might be linked to bed censors, all of which could be utilised at later dates as people age and develop a dementia.

8.3.2. Policy

The research shed light on aspects of public policy for people living with dementia which urgently need reform. For example, their long-term care needs tends to be almost exclusively catered for by the residential long-stay model of care, and there are limited examples of alternate models of long-term care as seen in other countries such as "housing with care" schemes and group home arrangements; approaches which would offer people living with dementia more independence and autonomy and that are seen in other countries. There is a need for a wide range of different housing options to be made available. In keeping with the NICE Quality Standards for dementia, there is a need for people who have dementia to be living in housing that meets their specific needs (NICE, 2013) and to be helped remain in their

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own homes and communities for as long as possible. Given the high costs of residential long-stay care, it would seem prudent that Nursing Home Support Scheme funding would be made available to families to enable them continue to provide community care. If home adaptation is considered vital for the sustainability of home care then we would recommend that this funding be made available to families.

In terms of policy development we would recommend that the Universal Design approach for dementia friendly dwellings should be incorporated into future iterations of key national housing strategies, policies, regulations and guidelines and for a more inter-sectoral approach to be taken to dementia care. For example, the national housing strategy for people with a disability, the housing policy framework, and documents such as delivering homes sustaining communities, or Part M (2010) of the technical guidance documents (TGD) must, where relevant, reflect some of the key findings from this research. In the light of the Irish government's policy commitment to community care for people living with dementia, the National Dementia Strategy needs to reflect ways by which government policy can realistically support older people living with dementia to continue living at home despite their disability.

Ultimately any policy documents affecting the living conditions of people living with dementia, their families and carers must be evidence-based and appropriate ethical and cost effective solutions must be employed. Taking on board the feedback received during the consultation process and based on stakeholder interviews for this study, where it was mentioned that architects, built environment professionals and builders are exposed to many different guidelines and policy, the dementia specific guidelines developed here must be collated in such a way that they are simple, succinct and easy to implement.

8.3.3. Research

Several research recommendations based on this study have already been incorporated into earlier parts of this report (See Section 6.4.). In summary we would recommend that more research be conducted on the topic of the home environment and how the latter can be best adapted to meet the unique and complex needs of people living with dementia, their families and carers. For example, it would be helpful to conduct a cross-sectional study with people who have mild to moderate dementia and who have adapted their homes using individual approaches to find out what has worked well for them, their families and carers and what has failed. Such experiences could then be disseminated to others. It would also be valuable to conduct a pilot study of a selection of different home dwellings recently adapted for people

living with dementia, their families and carers, which would incorporate pre-determined universally designed dementia friendly features. An evaluation study of this type could use a pre-test, post-test design and would generate helpful information about the success or otherwise of design features. A study like this would need to be carried out in close collaboration with people living with dementia, their families and carers and with relevant built environment professionals and health service professionals including Occupational Therapists.

There is a need for more research to be conducted on the use and usefulness of assistive technology and on the timing of when technologies in the context of the illness trajectory are most effective. There is a need for longitudinal research to track down changes in the home circumstances of people living with dementia over time and attempt to capture helpful data on the optimal time for certain design interventions to be introduced and monitored. There is a need for research to be conducted on aspects of design such as the merits and demerits of open plan versus more traditional enclosed room layout structures, a topic which will be discussed in the final design guidance report[21]. Proponents of open plan would argue that the latter promotes visual access, orientation and ease of mobility whilst those subscribing to the more traditional cellular plan, would favour it in terms of its familiarity and its capacity to provide distinct spaces for distinct activities.

We would also recommend that a demonstration unit or dwelling (similar to the Dutch model described in chapter six but adapted for Irish people) be designed in collaboration with all relevant health service professionals, social and behavioural scientists, architects, built environment professionals, design engineers, quantity surveyors, landscape architects, project managers and technology experts. This demonstration unit could act as a research and education resource to inform the relevant disciplines about key Universal Design and dementia friendly design practices, features and technology.

8.4. Conclusion

In conclusion the design guidelines have been accepted by the key stakeholders. They will be based on the recommendations arising from this report and will be applicable to both the retrofitting of existing dwellings along with the design from a Universal Design approach of new builds. Much of the material informing the specific guidelines will be drawn from chapter five of this report. The guidelines will be titled "Guidelines for a Universal Design Approach to

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[21] Our design guidance is based on best practice.

Dementia Friendly Dwellings". The relationship of these guidelines to relevant national housing strategies such as the National Housing Strategy for People with a Disability (2011-2016) and its implementation plan and the Housing Policy Framework, Building Sustainable Communities (2005) will be carefully mapped out. The document "Universal Design Guidelines for Homes in Ireland" will operate as the parent document with our newly developed dementia specific guidelines. Finally, for the successful use of guidelines we believe it is mandatory to carefully cross-reference and link together the two documents.

9. References

ALEXANDER, C., ISHIKAWA, S. & SILVERSTEIN, M. 1977. *A pattern language : towns, buildings, construction,* New York, Oxford University Press.

ALZHEIMER'S DISEASE INTERNATIONAL, 2013. Government Alzheimer Plans [Online]. Available: http://www.alz.co.uk/alzheimer-plans

ALZHEIMER SOCIETY OF IRELAND, 2013. *Clinicians Roundtable discussion on the National Dementia Strategy* [Online].
Available: http://www.alzheimer.ie/get-involved/campaigning/clinicans-roundtable-discussion-on-the-national-de.aspx [Accessed 02-05-2014].

ALZHEIMER SOCIETY OF IRELAND, 2014. *How does dementia progress?* [Online]. Available: http://www.alzheimer.ie/Living-with-dementia/I-have-Dementia/Stages-and-Progression.aspx [Accessed 01-05-2014]

ALZHEIMER'S SOCIETY UK, 2014 *Mobility Strategies* [Online]. Available: http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=1631 [Accessed: 02-05-2014]

Ancoli-Israel., S., Martin, J.L. , Gehrman, P. et al., (2003) 'Effect of light on agitation in institutionalised [atients with sever Alzheimer disease'*, American Journal of Geriatric Psychiatry,* 11: 194-203.

ANDERZHON, J., ET AL (2012). Design for aging: international case studies of building and program. New Jersey: John Wiley & Sons.

ARKSEY, H., & O'MALLEY, L. (2005). Scoping studies: towards a methodological framework. *International journal of social research methodology*, *8*(1), 19-32.

BAKKER, R. (2003) 'Sensory loss, dementia and environments,' *Generations,* 27(1): 46-51.

BARNES, C. (2011). Understanding disability and the importance of design for all.*Journal of accessibility and design for all*, *1*(1), 30.

BEGLEY, E. (2009) *"I know what it is but how bad does it get?": Insights into the Lived Experiences and Services Needs of People with Early-State Dementia,* Ph.D. thesis, Trinity College Dublin.

BERTRAND, R.M., FREDMAN, L. AND SACZYNSKI, J. (2006) 'Are all caregivers created equal? Stress in caregiving to adults with and without dementia', *Journal of Aging and Health,* 18(4): 534-51.

BRAND, S. 1995. *How Buildings Learn: What happens after they're built*, Penguin.

BRAUBACH, M., JACOBS, D.E. AND ORMANDY, D. (EDS.) (2011) *Environmental Burden of Disease associated with Inadequate Housing: Methods for Quantifying Health Impacts of Selected Housing Risks in the WHO European Region*, WHO European Region, Copenhagen. (Last accessed: 30.04.214. Available at http://www.euro.who.int/__data/assets/pdf_file/0003/142077/e95004.pdf?ua=1]

BRAWLEY, E.C. (2001) 'Environmental design for Alzheimer's disease: A quality of life issue', *Aging and Mental Health,* 5(S1): 79-83.

Burns, A., Byrne, J., Ballard, C. and Holmes, C. (2002) 'Sensory stimulation in dementia', *BMJ,* 325: 1313-1313.

BALDUCCI, A., CARDIA, C. & BOTTIGELLI, C. 2007. PLANNING URBAN DESIGN AND MANAGEMENT FOR CRIME PREVENTION - HANDBOOK. EUROPEAN COMMISSION - DIRECTORATE-GENERAL JUSTICE, FREEDOM AND SECURITY.

BLUYSSEN, P. M. 2009. *The indoor environment handbook : how to make buildings healthy and comfortable,* London; Sterling, VA, Earthscan.

BOBERSKY, A. 2013. *"It's been a good move". Transitions into care: Family caregivers', persons' with dementia, and formal staff members' experiences of specialist care unit placement* (Unpublished Ph.D. thesis). Trinity College Dublin, Ireland.

BREEAM. 2013. *Code for Sustainable Homes* [Online]. Available: http://www.breeam.org/page.jsp?id=86 [Accessed 22-08-13 2013].

BROPHY, V. & LEWIS, J. O. 2011. *A green vitruvius : principles and practice of sustainable architectural design,* London; Washington, DC, Earthscan.

Research for Dementia and Home Design in Ireland looking at New Build & Retro-Fit
Homes from a Universal Design Approach: Key Findings & Recommendations 2015

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BUILDING AND CONSTRUCTION AUTHORITY 2006. Universal Design guidelines (Commercial buildings). Singapore Government.

BURTON, E. & MITCHELL, L. 2006. *Inclusive urban design : streets for life,* Oxford, Architectural.

CAHILL, S. M. (1999). Caring in families: What motivates wives, daughters, and daughters-in-law to provide dementia care?. *Journal of Family Studies*, *5*(2), 235-247.

CAHILL, S., & DIAZ-PONCE, A. M. (2011). 'I hate having nobody here. I'd like to know where they all are': Can qualitative research detect differences in quality of life among nursing home residents with different levels of cognitive impairment?.*Aging & mental health*, *15*(5), 562-572.

CAHILL, S., O'SHEA, E. & PIERCE, M 2012. Creating Excellence in Dementia Care. A research review for Ireland's National Dementia Strategy. DSIDC's Living with Dementia Research Programme, School of Social Work and Social Policy, Trinity College Dublin; in association with Irish Centre for Social Gerontology, National University of Galway, Ireland.

CAHILL, S., PIERCE, M. & BOBERSKY, A. (2014). An *Evaluation Report on the Dementia Support Worker Initiative of the 5 Steps to Living with Dementia in South Tipperary,* Trinity College Dublin and Genio, Dublin and Mullingar.

CAHILL, S., PIERCE, M. & BOBERSKY, A. (2014). *An Evaluation of Flexible Respite Options of the Living Well with Dementia Project in Stillorgan and Blackrock,* Trinity College Dublin and Genio, Dublin and Mullingar.

CALKIN, M. (2002) How colour throws light on design in dementia care, *Journal of Dementia Care,*10(4): 20-23.

CALKINS, M. P. 1987. Designing Special Care Units: A Systematic Approach — Part II. *American Journal of Alzheimer's Disease and Other Dementias,* 2**,** 30-34.

CALKINS, M. P. 1988. *Design for dementia : planning environments for the elderly and the confused,* Owings Mills, Md., National Health Pub.

CALKINS, M. P. 2001. Design for Dementia: Challenges and lessons for Universal Design . *In:* PREISER, W. F. E. & ELAINE, O. (eds.) *Universal Design Handbook 1E.* New York: McGraw-Hill Professional.

CALKINS, M. P. (2009). Evidence-based long term care design.*NeuroRehabilitation*, *25*(3), 145-154.

CALKINS, M. P. & SLOANE, P. D. 2013. *Designing a Care Facility* [Online]. Alzheimer's Association. Available: http://www.alz.org/professionals_and_researchers_designing_a_care_facility.asp [Accessed 02-02 2013].

CANTLEY, 2007. 'Problems in evaluating dementia care' in Innes, A. and McCabe, L. (eds.) *Evaluation in Dementia Care,* Jessica Kingsley Publishers, London, pp. 20-45.

CEN 2005. Prevention of crime - Urban planning and building design - Part 3: Dwellings. *Technical Specification - CEN/TS 14383-3.* EUROPEAN COMMITTEE FOR STANDARDIZATION (CEN),.

CEN 2007. Prevention of crime - Urban planning and building design - Part 2: Urban planning. *Technical Specification - CEN/TS 14383-2.* EUROPEAN COMMITTEE FOR STANDARDIZATION (CEN),.

CENTER FOR EXCELLENCE IN UNIVERSAL DESIGN . 2012. *Buildings for Everyone: A Universal Design Approach* [Online]. Available: http://universaldesign.ie./guidelinesampstandards/builtenvironment/buildingforeveryone [Accessed 30-08-12 2012].

CENTRE FOR EXCELLENCE IN UNIVERSAL DESIGN 2012. Buildings for Everyone: A Universal Sesign Approach. Dublin, CEUD.

CENTRE FOR EXCELLENCE IN UNIVERSAL DESIGN. 2013. *Universal Design Guidelines for Homes in Ireland* [Online]. Available: http://www.universaldesign.ie/files/udhi/UDHI.pdf [Accessed 01-05-2014].

CENTER FOR UNIVERSAL DESIGN . 1997. *The Principles of Universal Design* [Online]. Available: http://www.ncsu.edu/project/design-projects/udi/center-for-universal-design/the-principles-of-universal-design/ [Accessed 01-04-13 2013].

CENTER FOR UNIVERSAL DESIGN. 2008. *The Principles of Universal Design* [Online]. Available: http://www.ncsu.edu/ncsu/design/cud/about_ud/udprinciplestext.htm [Accessed 01-05-2014]

CENTRAL STATISTICS OFFICE (2010) Quarterly National Household Survey: Carers, Quarter 3 2009, Central Statistics Office, Dublin and Cork.

CENTRAL STATISTICS OFFICE (2012) Census 2011 Our Bill of Health – Health, Disability and Carers

in Ireland, Stationary Office, Dublin. [Last accessed 26.04.2014; Available from
http://www.cso.ie/en/media/csoie/census/documents/census2011profile8/Profile,8,Full,document.pdf].

CENTRAL STATISTICS OFFICE 2013. Census 2011 Profile 4 The Roof over our Heads - Housing in Ireland, Statinary Office, Dublin.

CHAUDHURY, H. (2002). Journey back home: Recollecting past places by people with dementia. *Journal of Housing for the Elderly*, *16*(1-2), 85-106.

CLARKE, C. L., WILCOCKSON, J., GIBB, C. E., KEADY, J., WILKINSON, H., & LUCE, A. (2011). Reframing risk management in dementia care through collaborative learning. *Health & social care in the community*, *19*(1), 23-32.

COHEN, U., & DAY, K. (1993). *Contemporary environments for people with dementia*. Baltimore, MD: Johns Hopkins University Press.

COHEN, U. & WEISMAN, G. D. 1991. *Holding on to home : designing environments for people with dementia,* Baltimore, Johns Hopkins University Press.

COHEN-MANSFIELD, J. 2001. Nonpharmacologic interventions for inappropriate behaviors in dementia: a review, summary, and critique. *The American Journal of Geriatric Psychiatry*, *9*(4), 361-381.

COOPER MARCUS, C. & SARKISSIAN, W. 1986. *Housing as if people mattered : site design guidelines for medium-density family housing,* Berkeley, University of California Press.

CONNOLLY, M, 2011. *Assistive technology in the homes of people with dementia* [Power Point]. Available:https://www.google.ie/search?q=connolly+dementia+assistive+technology+home&oq=connolly+dementia+assistive+technology+home&aqs=c [Accessed: 02-05-2014].

CONNOLLY, S., GILLESPIE, P., O'SHEA, E., CAHILL, S., & PIERCE, M. 2014. Estimating the economic and social costs of dementia in Ireland. *Dementia*,*13*(1), 5-22.

CONVERY, J, (2014). Title. Unpublished Ph.D. thesis). Trinity College Dublin, Ireland.

COX, S. 2006. *Home Solutions 2- Housing, Care and Support for People with Dementia.* Stirling, United Kingdom: University of Stirling - The Dementia Services Development Centre (DSDC).

CRAM, F., & PATON, H. (1993). Personal Possessions and Self-Identity: The Experiences of Elderly Women in three Residential Settings. *Australasian Journal on Ageing*, *12*(1), 19-24.

CREWS, D. E., & ZAVOTKA, S. (2006). Aging, disability, and frailty: implications for universal design. *Journal of physiological anthropology*, *25*(1), 113.

CULLEN, K., MCANANEY, D., DOLPHIN, C., DELANEY, S. & STAPLETON, P. 2012. Research on the provision of Assistive Technology in Ireland and other countries to support independent living across the life cycle.

DAVIS, S., BYERS, S., NAY, R., & KOCH, S. 2009. Guiding design of dementia friendly environments in residential care settings: considering the living experiences. *Dementia*, *8*(2), 185-203.

DAY, K. & CALKINS, M. P. 2002. Design and dementia (374-393) *In:* BECHTEL, R. B. & CHURCHMAN, A. (eds.) *Handbook of environmental psychology*, New York, Wiley & Sons.

DAY, K., CARREON, D., & STUMP, C. 2000. The therapeutic design of environments for people with dementia a review of the empirical research. *The Gerontologist*, *40*(4), 397-416.

DECLG 2005. Part L- Sound - Building Regulations 2005. Dublin: The stationery Office Dublin.

DECLG 2011. Part L- Conservation of Fuel and Energy - Dwellings - Building Regulations 2011. Dublin: The stationery Office Dublin.

DECLG 2000. Part M-Access for People with Disabilities- Building Regulations 2000. Dublin: The stationery Office Dublin.

DEHLG 2007. Quality Homes for Sustainable Communities: Best Practice Guidelines for Quality Housing for Sustainable Communities. Dublin: The stationery Office Dublin.

DEHLG 2009. Delivering homes sustaining communities – Statement on housing policy. Dublin: The stationery Office Dublin.

DEHLG 2009a. Guidelines for Planning Authorities on Sustainable Residential Development in Urban Areas (Cities, Towns & Villages). Dublin: The stationery Office Dublin.

DEHLG 2009b. Urban Design Manual: A best practice guide. Dublin: The stationery Office Dublin.

DECLG 2010. Part M-Access and Use- Building Regulations 2010. Dublin: The Stationery Office Dublin.

DEMENTIA ENABLING ENVIRONMENTS. 2013. *Dementia Enabling Environments* [Online]. Available:
        http://www.enablingenvironments.com.au [Accessed 02-04-13 2013].

DEPARTMENT OF HEALTH 2013. *National Positive Ageing Strategy* [Online]. Available:
        http://www.dohc.ie/publications/National_Positive_Ageing_Strategy.html [Accessed 02-05-
        2014]

DECLG (DEPARTMENT OF THE ENVIRONMENT, COMMUNITY AND LOCAL GOVERNMENT) & DOH
        (DEPARTMENT OF HEALTH) (2012) *National Housing Strategy for People with a Disability, 2011-
        2016: National Implementation Framework,* DECLG and DoH, Dublin.

DIAZ, A. 2014. *Quality of life and anti-dementia medication: An exploration of the experiences of people
        living with dementia and their care-partners* (Unpublished Ph.D. thesis). Trinity College Dublin,
        Ireland.

DSDC, 2010. *10 Helpful Hints for Dementia Design at Home: Practical Design Solutions for Carers Living
        at Home with Someone Who has Dementia,* Dementia Services and Development Centre,
        University of Stirling, Stirling.

DSDC. 2013. *Improving the design of housing to assist people with dementia,* DSDC Stirling, Scotland

DUGGAN, S., BLACKMAN, T., MARTYR, A., & VAN SCHAIK, P. (2008). The impact of early dementia on
        outdoor life Ashrinking world'?. *Dementia*, *7*(2), 191-204.

DUNCAN, R. Universal Design . *In:* NDA, C., ed. Universal Design for the 21st Century: Irish and
        International Perspectives, 2007 Dublin. Centre for EXcellence in Universal Design / National
        Disability Authority

EASTON, 2014. Personal Communication

EDWARDS, B. & TURRENT, D. 2000. *Sustainable housing : principles & practice,* London; New York, E &
        FN Spon.

EISDORFER, C. & LAWTON, M. P. 1973. *The psychology of adult development and aging,* Washington,
        American Psychological Association.

ERIKSSON, S. (2010). Developments in dementia strategy. *International Journal of Geriatric
        Psychiatry*, *25*(9), 885-886.

EUROPEAN COMMISSION, 2009. *Communication from the Commission to the European Parliament and
        the Council on a European Initiative on Alzheimer's disease and other dementias* [Online].
        Available:http://ec.europa.eu/health/archive/ph_information/dissemination/documents/com2
        009_380_en.pdf [Accessed: 02-05-2014]

FENNELL, P. ET AL. (2010). Institutionalising the community: The codification of clinical authority and the
        limits of rights-based approaches. *Rethinking rights-based mental health laws*, 13-50.

FLEMING, R., CROOKES, P. A., & SUM, S. 2008. A review of the empirical literature on the design of
        physical environments for people with dementia.

FLEMING, R., & PURANDARE, N. 2010. Long-term care for people with dementia: environmental design
        guidelines. *International Psychogeriatrics*, *22*(07), 1084-1096.

FRIEDMAN, A. 2002. *The adaptable house : designing homes for change,* London, McGraw-Hill.

FROYEN, H. 2012. *Universal Design , a Methodological Approach*, The Institute for Human Centered
        Design.

GARAVAN, R., WINDER, R., & MCGEE, H. (2001). Health and social services for older people
        (HeSSOP). *Dublin: National Council on Ageing and Older People*.

GIBSON, J. J. 1979. *The ecological approach to visual perception,* Boston, Houghton Mifflin.

GILMOUR, H., GIBSON, F., & CAMPBELL, J. 2003. Living Alone with Dementia A Case Study Approach to
        Understanding Risk. *Dementia*, *2*(3), 403-420.

GIRARDET, H. & SCHUMACHER, S. 1999. *Creating sustainable cities,* Totnes, Devon, Published by Green
        Books for The Schumacher Society.

GITLIN, L.N. (2003) Conducting research on home environments: Lessons learned and new
        Directions, *The Gerontologist,* 43(5), 628-637.

GOLDSMITH, S. 2001. *Universal Design* [Online]. Burlington: Elsevier. Available:
        http://public.eblib.com/EBLPublic/PublicView.do?ptiID=298043.

GOLDSMITH, M. (1996). *Hearing the voice of people with dementia: Opportunities and obstacles*. Readers Digest.

GOODMAN, P., MCAVOY, H., COTTER, N., MONAHAN, E., BARRETT, E., BROWNE, S., ET AL. (2011) *Fuel Poverty, Older People and Cold Weather: An All-island Analysis,* Dublin Institute of Technology, Dublin.

GOODMAN, C., EVANS, C., WILCOCK, J., FROGGATT, K., DRENNAN, V., SAMPSON, E., ... & ILIFFE, S. (2010). End of life care for community dwelling older people with dementia: an integrated review. *International journal of geriatric psychiatry,25*(4), 329-337.

GOODMAN, C. & HABINTEG HOUSING ASSOCIATION 2011. *Lifetime Homes design guide,* Bracknell, BRE.

HAGEN, I., HOLTHE, T., GILLIARD, J., TOPO, P., CAHILL, S., BEGLEY, E., ... & ENGEDAL, K. 2004. Development of a protocol for the assessment of assistive aids for people with dementia. *Dementia*, *3*(3), 281-296.

HIQA 2009. *National Quality Standards for Residential Care Settings for Older People in Ireland*, Health Information and Quality Authority, Dublin and Cork.

HEMINGWAY, L. (2011). *Disabled people and housing: Choices, opportunities and barriers*. The Policy Press.

HESTERMAN, D. 2011. *Stanford climate scientists forecast permanently hotter summers beginning in 20 years* [Online]. Stanford. Available: http://news.stanford.edu/news/2011/june/permanent-hotter-summers-060611.html [Accessed 28-08-13 2013].

HEYMAN, OLDMAN, MEANS (2002) --

HOUSING LEARNING AND IMPROVEMENT NETWORK, 2009. *Homes for our old age* [Online]. Available: https://www.designcouncil.org.uk/sites/default/files/asset/document/homes-for-our-old-age.pdf [Accessed 02-05-2014]

IMRIE, R. & HALL, P. 2001. Inclusive design: designing and developing accessible environments, New York, Taylor & Francis.

INNES, A., KELLY, F., & DINCARSLAN, O. 2011. Care home design for people with dementia: What do people with dementia and their family carers value?. *Aging & mental health*, *15*(5), 548-556.

INSTITUTE OF AGING AND ENVIRONMENT, I.D.E.A.S. INC & POLISHER RESEARCH INSTITUTE. 2013. *Dementia Design Info* [Online]. Available: https://www4.uwm.edu/dementiadesigninfo/.

INSTITUTE OF PUBLIC HEALTH IN IRELAND 2006. *Health Impacts of the Built Environment. A Review* [Online]. Available: http://www.publichealth.ie/sites/default/files/documents/files/Health_Impacts_of_the_Built_Environment_A_Review.pdf [Accessed 30-04-2014].

INTER-DEPARTMENTAL COMMITTEE ON THE CARE OF THE AGED (1968), *The Care of the Aged,* Stationery Office, Dublin.

JOHANSSON, L., CHRISTENSSON, L., & SIDENVALL, B. (2011). Managing mealtime tasks: told by persons with dementia. *Journal of clinical nursing*, *20*(17-18), 2552-2562.

JOHNSTON, D., SAMUS, Q. M., MORRISON, A., LEOUTSAKOS, J. S., HICKS, K., HANDEL, S., ... & BLACK, B. S. 2011. Identification of community-residing individuals with dementia and their unmet needs for care. *International journal of geriatric psychiatry*, *26*(3), 292-298.

JONES, R., & TRIGG, R. 2007. Dementia and Serious Sight Loss. *Research Institute for the Care of the Elderly, St Martin's Hospital, Bath, UK (Occasional Paper No. 11*, 1-18.

JORDAN, W. A. 2008. *Universal Design for the home : great looking, great living design for all ages, abilities, and circumstances,* Beverly, Mass., Quarry Books.

JUDD, S., PHIPPEN, P. & MARSHALL, M. 1998. *Design for dementia,* London, Journal of Dementia Care.

KAHANA, E. 1974. Matching environments to the needs of the aged: A conceptual scheme. *In:* GUBRIUM, J. F. (ed.) *Late life; communities and environmental policy.* Springfield, Ill.: Thomas.

KAHANA, E., LOVEGREEN, L., KAHANA, B. & KAHANA, M. 2003. Person, Environment, and Person-Environment Fit as Influences on Residential Satisfaction of Elders. *Environment and Behavior,* 35**,** 434-453.

KAMIYA, Y., MURPHY, C., SAAVA, G. AND TIMONEN, V. (2012) *Profile of Community-Dwelling Older People with Disability and their Caregivers in Ireland,* The Irish Longitudinal Study on Ageing, Dublin.

KEENE, J., HOPE, T., FAIRBURN, C. G., & JACOBY, R. (2001). Death and dementia.*International journal of geriatric psychiatry*, *16*(10), 969-974.

KOSE, S., PREISER, W. & OSTROFF, E. 2001. *Universal Design handbook*.

KOSS, E. & GILMORE, G. C. (1999). Environmental intervention to improve performance and slow functional decline in persons with dementia. The gerontologist, 39, 193.

KRAMER, B. J., & KIPNIS, S. (1995). Eldercare and work-role conflict: Toward an understanding of gender differences in caregiver burden. *The Gerontologist*,*35*(3), 340-348.

KRAUSS, I. 2011. Manifestations of Universal Design in Germany. *In:* PREISER, W. F. E. & ELAINE, O. (eds.) *Universal Design Handbook 2E.* New York: McGraw-Hill Professional.

LANDCOM 2008. Universal housing design guidelines New South Wales, Australia.

LAVIN, T., HIGGINS, C., METCALFE, O., & JORDAN, A. (2006). Health Impacts of the Built Environment. *A Review. Dublin: Institute of Public Health in Ireland*.

LAWRENCE, V., MURRAY, J., & BANERJEE, S. 2009. "Out of sight, out of mind": a qualitative study of visual impairment and dementia from three perspectives.*International psychogeriatrics*, *21*(03), 511-518.

LAWTON, M. P. 1977. The impact of the environment on aging and behavior. *In:* BIRREN, J. E. & SCHAIE, K. W. (eds.) *Handbook of the psychology of aging.* New York: Van Nostrand Reinhold.

LAWTON, M. P., WINDLEY, P. G. & BYERTS, T. O. 1982. *Aging and the environment : theoretical approaches,* New York, Springer.

LAWTON, M. P. 1983. Environment and Other Determinants of Weil-Being in Older People. *The Gerontologist,* 23**,** 349-357.

LAWTON, M. P. 1989. Environmental approaches to research and treatment of Alzheimer's Disease *In:* LIGHT, E. & LEBOWITZ, B. (eds.) *Alzheimer's disease treatment and family stress : directions for research.* Rockville, Md.; Washington, D.C.: U.S. Dept. of Health and Human Services, Public Health Service, Alcohol, Drug Abuse, and Mental Health Administration, National Institute of Mental Health ; For sale by the Supt. of Docs., U.S. G.P.O.

LAWTON, M. P. 2001a. Designing by degree: Assessing and incorporating individual accessibility needs. *In:* PREISER, W. F. E. & ELAINE, O. (eds.) *Universal Design Handbook 1E.* New York: McGraw-Hill Professional.

LAWTON, M. P. 2001b. The Physical Environment of the person with Alzheimer's disease. *Aging and Mental Health* 5**,** S56-S64.

LAWTON, M. P., FULCOMER, M. & KLEBAN, M. H. 1984. Architecture for the Mentally Impaired Elderly. *Environment and Behavior,* 16**,** 730-757.

LAWTON, M. P., WINDLEY, P. G. & BYERTS, T. O. 1982. *Aging and the environment : theoretical approaches,* New York, Springer.

LEWIS, S. C. 2003. *Elder care in occupational therapy*, Slack Incorporated.

LIDWELL, W., HOLDEN, K. & BUTLER, J. 2010. *Universal Principles of Design, Revised and Updated. ; 115 Ways to Enhance Usability, Influence Perception, Increase Appeal, Make Better Design Decisions, and Teach through Design*.

LOBO, A., LAUNER, L.J., FRATIGLIONI, L., ANDERSEN, K., DI CARLO, A., BRETELER, M.M., COPELAND, J.R., DARTIGUES, J.F., JAGGER, C., MARTINEZ-LAGE, J., SOININEN, H., AND HOFMAN, A. 2000 Prevalence of dementia and major subtypes in Europe: A collaborative study of population-based cohorts, *Neurology, 54*(11), Supplement 5: S4-S9.

LUNDH, U., NOLAN, M., HELLSTROM, I., & ERICSSON, I. (2003). Quality care for people with dementia: The views of family and professional carers. *Partnerships in family care: Understanding the caregiving career*, 72-89.

MACE, R. L. (1998). Universal design in housing. *Assistive Technology*, *10*(1), 21-28.

MAKI, O. & TOPO, P. 2009. Needs and user requirements of people with dementia: Multimedia Application for Entertainment. *In:* TOPO P., Östlund. B. (ed.) *Dementia, Design and Technology Time to Get Involved. Assistive Technology Research Series, Volume 24.* IOS Press.

MARQUARDT, G., JOHNSTON, D., BLACK, B. S., MORRISON, A., ROSENBLATT, A., LYKETSOS, C. G., & SAMUS, Q. M. 2011. A descriptive study of home modifications for people with dementia and barriers to implementation. *Journal of Housing for the Elderly*, *25*(3), 258-273.

MARQUARDT, G., & SCHMIEG, P. 2009. Dementia-friendly architecture: environments that facilitate wayfinding in nursing homes. *American journal of Alzheimer's disease and other dementias*, *24*(4), 333-340.

MARSHALL, M. 1998. Therapeutic buildings for people with dementia *In:* JUDD, S., PHIPPEN, P. & MARSHALL, M. (eds.) *Design for dementia.* London: Journal of Dementia Care.

MARSHALL, M. 2001. The challenge of looking after people with dementia: Professional carers need higher expectations and better training and support.*BMJ: British Medical Journal*, *323*(7310), 410.

MARSHALL, M. 2009. The needs of people with dementia and their carers and the potential role of design and technology. *In:* TOPO P, Ö. B. (ed.) *Dementia, Design and Technology Time to Get Involved. Assistive Technology Research Series, Volume 24.* IOS Press.

MARSHALL, M. 2010 --

MASLOW, A. H. 1970. *Motivation and personality,* New York, Harper & Row.

MEANEY, A. M., CROKE, M., & KIRBY, M. (2005). Needs assessment in dementia.*International Journal of Geriatric Psychiatry*, *20*(4), 322-329.

MIRANDA-CASTILLO, C., WOODS, B., & ORRELL, M. (2010). People with dementia living alone: what are their needs and what kind of support are they receiving?.*International Psychogeriatrics*, *22*(04), 607-617.

MITCHELL, S. L., TENO, J. M., MILLER, S. C., & MOR, V. (2005). A national study of the location of death for older persons with dementia. *Journal of the American Geriatrics Society*, *53*(2), 299-305.

NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE 2011. *The NICE -SCIE Guideline on supporting people with dementia and their carers in health and social care* [Online]. Available: http://www.nice.org.uk/nicemedia/live/10998/30320/30320.pdf [Accessed 01-05-2014]

NATIONAL RESEARCH COUNCIL (2011) *Health Care Comes Home: The Human Factors,* Committee on the Role of Human Factors in Home Health Care, Board on Human-Systems Integration, Division of Behavioral and Social Sciences and Education, The National Academies Press, Washington D.C.

NEISTADT, M. 2000. *Occupational therapy evaluation for adults: a pocket guide*, LIPPINCOTT RAVEN.

NICE (2013) *Quality Standard to Support People to Live Well with Dementia, QS30,* [Available at http://publications.nice.org.uk/quality-standard-for-supporting-people-to-live-well-with-dementia-qs30]

NICOL, J. F. & HUMPHREYS, M. A. 2002. Adaptive thermal comfort and sustainable thermal standards for buildings. *Energy and Buildings,* 34**,** 563-572.

NORMAN, D. A. 2002. *The design of everyday things,* New York, Basic Books.

NORRIS, M., & WINSTON, N., 2008, *Rising Second home numbers in rural Ireland: distribution, drivers and implications.* Paper presented to the UK Ireland Planning Research Conference, Queen's University, Belfast; copy available from M. Norris, School of Applied Social Science, University College Dublin, Dublin.

NORWEGIAN MINISTRY OF HEALTH AND CARE SERVICES 2008. Subplan of Care Plan 2015: Dementia Plan 2015 [Online]. Available: http://www.regjeringen.no/upload/HOD/Dokumenter%20KTA/DementiaPlan2015.pdf. [Accessed 02-5-2014]

NYGÅRD, L. 2004. Responses of persons with dementia to challenges in daily activities: A synthesis of findings from empirical studies. *The American journal of occupational therapy*, *58*(4), 435-445.

NYGARD, L., & OEHMAN, A. 2002. Managing changes in everyday occupations: The experience of persons with Alzheimer's disease. *Occupational Therapy Journal of Research,* *22,* 70–81.

OFFICE OF THE ATTORNEY GENERAL, 2005. *Disability Act 2005* [Online]. Available: http://www.irishstatutebook.ie/2005/en/act/pub/0014/ [Accessed: 02-05-2-14]

O'HANLON, A., MCGEE, H., BARKER, M., GARAVAN, R., HICKEY, A., CONROY, R.
AND O'NEILL, D. (2005), *Health and Social Services for Older People II (HeSSOP II): Changing Profiles from 2000 to 2004,* National Council on Ageing and Older People, Dublin.

O'MALLEY, L., & CROUCHER, K. 2005. Housing and dementia care–a scoping review of the literature. *Health & social care in the community*, 13(6), 570-577.

O'SHEA, E. (2000) *The Costs of Caring for People with Dementia and Related Cognitive Impairments*, Report No. 60, National Council on Ageing and Older People, Dublin.

O'SHEA, E. (2003) 'Costs and consequences for carers of people with dementia in Ireland, *Dementia: The International Journal of Research and Practice,* 2(2): 201-19.

O'SHEA, E. 2007. Implementing policy for dementia care in Ireland: The time for action is now [Online]. Available: http://lenus.ie/hse/handle/10147/196455 [Accessed 02-05-2014].

O' SHEA, E & O'REILLY, S. 1999. An Action Plan for Dementia. Dublin: National Council on Ageing and Older People.

OLESEN, B. 2002. Radiant floor heating in theory and practice. *ASHRAE J,* 44**,** 19-26.

ORPWOOD, R. 2009. Invloving people with dementia in the design process - Examples of Iterative Design. *In:* TOPO P, Ö. B. (ed.) *Dementia, Design and Technology Time to Get Involved. Assistive Technology Research Series, Volume 24.* IOS Press.

ORY, M.G., HOFFMAN, R.R., YEE, R.R., TENNSTEDT, S., & SCHULZ, R. (1999) 'Prevalence and impact of caregiving: A detailed comparison between dementia and non-dementia caregivers', *Gerontologist,* 39: 771-91

OSTROFF, E. (2010). Universal design: an evolving paradigm. PREISER, W. F. E. & Smith, K. H. (eds.) *Universal design handbook, 2E*, 1-3. New York, McGraw-Hill Professional.

PIERCE, M., CAHILL, S. AND O'SHEA, E. (2014) *Prevalence and Projections of Dementia, 2011,* Genio, Mullingar.

PINQUART, M. & SÖRENSEN, S. (2003) 'Associations of stressors and uplifts of caregiving with caregiver burden and depressive mood: A meta-analysis', *Journal of Gerontology: Psychological Sciences*, *58B*, 112-28.

PHINNEY, A. (1998). Living with dementia from the patient's perspective. *Journal of Gerontological Nursing, 24,* 3–15.

PHINNEY, J. A. (2000). *Sustaining meaning in the midst of breakdown: And interpretive phenomenological study of symptom experience in dementia.* Unpublished doctoral dissertation, University of California, San Francisco.

PHINNEY, A. (2006). Family strategies for supporting involvement in meaningful activity by persons with dementia. *Journal of Family Nursing*, *12*(1), 80-101.

PHINNEY, A. (2008). Toward understanding subjective experiences of dementia.In: DOWNS, M. & BOWERS B. (eds.) *Excellence in dementia care: Research into practice*, 35-51, New York, McGraw-Hill.

PHINNEY, A., CHAUDHURY, H., & O'CONNOR, D. L. 2007. Doing as much as I can do: The meaning of activity for people with dementia. *Aging and Mental Health*,*11*(4), 384-393.

PHINNEY, A., & CHESLA, C. A. (2003). The lived body in dementia. *Journal of Aging Studies*, *17*(3), 283-299.

POLLOCK, A. 2001. *Designing gardens for people with dementia,* Stirling, University of Stirling, Dementia Services Development Centre.

POLLOCK, A. & MARSHALL, M. 2012. *Designing outdoor spaces for people with dementia,* Greenwich, N.S.W., HammondPress.

POLLOCK, R. & DSDC. 2003. *Designing interiors for people with dementia,* Stirling, Dementia Services Development Trust.

POLLOCK, R., DSDC. & INSTITUTION OF LIGHTING, E. 2008. *Designing lighting for people with dementia,* Stirling, Dementia Services Development Centre, University of Stirling.

POOLE, 2006 --

PREISER, W. F. E. & SMITH, K. H. (eds.) 2011. *Universal Design Handbook 2E,* New York: McGraw-Hill Professional.

221

PRINCE, M., PRINA, M. & GUERCHET, M. (2013) *World Alzheimer Report 2013 - Journey of Caring: An Analysis of Long-term Care for Dementia,* Alzheimer's Disease International, London.

PULSFORD, D., & THOMPSON, R. (2012). *Dementia: Support for Family and Friends*. Jessica Kingsley Publishers.

QURESHI H. & WALKER, A. (1989). *The Caring Relationship: Elderly People and their Families. Philadelphia.* Temple University Press

REIMER, M. A., SLAUGHTER, S., DONALDSON, C., CURRIE, G., & ELIASZIW, M. (2004). Special care facility compared with traditional environments for dementia care: a longitudinal study of quality of life. *Journal of the American Geriatrics Society, 52*(7), 1085-1092.

RIAI 2006. Cost Guidelines a consumer guide by the RIAI for 2006.

RIESER, R. 2004. *Disabling imagery? : a teaching guide to disability and moving image media,* London, BFI Education : Disability Equality in Education.

ROBINSON, L., HUTCHINGS, D., CORNER, L., BEYER, F., DICKINSON, H., VANOLI, A., ... & BOND, J. 2006. A systematic literature review of the effectiveness of non-pharmacological interventions to prevent wandering in dementia and evaluation of the ethical implications and acceptability of their use. *Health technology assessment (Winchester, England)*, *10*(26), iii-ix.

SANDHU, J. 2011. The Rhinoceros Syndrome: A contarian view of Universal Design . *In:* PREISER, W. F. E. & ELAINE, O. (eds.) *Universal Design Handbook 2E.* New York: McGraw-Hill Professional.

SANFORD, J. A. 2012. *Universal Design as a rehabilitation strategy: Design for the ages,* New York, NY US, Springer Publishing Co.

SATTARI, S. & FARHANIEH, B. 2006. A parametric study on radiant floor heating system performance. *Renewable Energy,* 31**,** 1617-1626.

SCARBOROUGH, B. K., LIKE-HAISLIP, T. Z., NOVAK, K. J., LUCAS, W. L. & ALARID, L. F. 2010. Assessing the relationship between individual characteristics, neighborhood context, and fear of crime. *Journal of Criminal Justice,* 38**,** 819-826.

SCHNEIDER, J., HALLAM, A., ISLAM, M. K., MURRAY, J., FOLEY, B., ATKINS, L., ... & MANN, A. (2003). Formal and informal care for people with dementia: variations in costs over time. *Ageing and Society*, *23*(3), 303-326.

SCHWARTZ, A. N. 1974. A transactional view of the aging process. *In:* SCHWARTZ, A. N. & MENSH, I. N. (eds.) *Professional obligations and approaches to the aged.* Springfield, Ill.: Thomas.

SCSI 2013. Are you fully insured? - Guide to house rebuilding costs 2013. Society of Chartered Surveyors Ireland.

SEAI 2008. Energy in the Residential Sector - 2008 Report Dublin.

SEAI 2012. Effecient home heating - your options. Dublin.

SEAI 2013. Energy in the Residential Sector - 2013 Report Dublin.

SLOANE, P. D., ZIMMERMAN, S., GRUBER-BALDINI, A. L., HEBEL, R., MAGAZINER, J. & KONRAD, T. R. 2005. Health and functional outcomes and health care utilization of persons with dementia in residential care and assisted living facilities. Comparison with nursing homes. *Gerontologist 45 (Special Issue 1)*, 124-132.

SMITH, R. C. 2002. The Biopsychosocial Revolution. *Journal of General Internal Medicine,* 17**,** 309-310.

SMITH, M., GERDNER, L. A., HALL, G. R., & BUCKWALTER, K. C. (2004). History, development, and future of the progressively lowered stress threshold: a conceptual model for dementia care. *Journal of the American Geriatrics Society*, *52*(10), 1755-1760.

STEINFELD, E. 2002. Caregiver focus. My father's room. *Alzheimer's Care Quarterly,* 3**,** 1-6.

STEINFELD, E. & MAISEL, J. 2012. *Universal Design : creating inclusive environments,* Hoboken, John Wiley & Sons, Inc.

SUSTAINABLE ENERGY IRELAND 2008. *Passive homes : guidelines for the design and construction of passive house dwellings in Ireland,* Clonakilty, County Cork, Sustainable Energy Ireland.

TEMZSTEDT, S. L., & SCHULZ, R. (2000). The extent and impact of dementia care: Unique challenges experienced by family caregivers. *Handbook on dementia caregiving: Evidence-based interventions for family caregivers*, 1, New York, Springer.

222

THOMAS, P., LALLOUÉ, F., PREUX, P. M., HAZIF-THOMAS, C., PARIEL, S., INSCALE, R., ... & CLÉMENT, J. P. (2006). Dementia patients caregivers quality of life: the PIXEL study. *International journal of geriatric psychiatry*, *21*(1), 50-56.

TIAN, Z. & LOVE, J. A. 2008. A field study of occupant thermal comfort and thermal environments with radiant slab cooling. *Building and Environment,* 43**,** 1658-1670.

TIMLIN, G. & RYSENBRY, N. 2010. Design for dementia: Improving dining and bedroom environments in caere homes London: Helen Hamlyn Centre, Rolay College of Art.

TIMONEN, V., KAMIYA, Y., & MATY, S. 2011. 4. Social Engagement Of Older People. *Fifty Plus in Ireland 2011*, 51.

TINKER, A. 2014. *The long-term care revolution. Lessons from abroad* [Power Point Slides]. Available: http://www.housinglin.org.uk/Events/ECHAnnualConference2014/ [Accessed 01-05-2014]

TORRINGTON, J. (2007). Evaluating quality of life in residential care buildings.*Building Research & Information*, *35*(5), 514-528.

TORRINGTON, J. M., & TREGENZA, P. R. (2007). Lighting for people with dementia.*Lighting Research and Technology*, *39*(1), 81-97.

TRIGG, R & JONES, R. 2005. Dementia and blindness. *Research Findings 6*, Thomas Pocklington Trust.

TWIGG, J. (2000) *Bathing: The Body and Community Care,* Routledge, London.

UNGERSON, C. (1995). Gender, cash and informal care: European perspectives and dilemmas. *Journal of Social Policy*, *24*, 31-31.

UNGERSON, C. (1987). *Policy is personal: Sex, gender and informal care*. London, Tavistock.

UNITED NATIONS. 2005. *2005 World Summit Outcome* [Online]. New York: United Nations.

UNITED NATIONS, 2006. *Convention on the rights of persons with disabilities* [Online]. Available: http://www.un.org/disabilities/convention/conventionfull.shtml [Accessed: 02-05-2014]

USGBC. 2013. *LEED Homes* [Online]. Available: http://www.usgbc.org/leed/rating-systems [Accessed 22-08-13 2013].

UTTON, D. (2007). *Designing homes for people with dementia*. Journal of Dementia Care, Hawker Publications.

UTTON, D. 2009. The design of housing for people with dementia. *Journal of Care Services Management*, *3*(4), 380-390.

VAN HOOF, J., BLOM, M. M., POST, H. N. A. & BASTEIN, W. L. 2013. Designing a "Think-Along Dwelling" for People With Dementia: A Co-Creation Project Between Health Care and the Building Services Sector. *Journal of Housing For the Elderly,* 27**,** 299-332.

VAN HOOF, J. & KORT, H. S. M. 2009. Supportive living environments: A first concept of a dwelling designed for older adults with dementia. *Dementia,* 8**,** 293-316.

VAN HOOF, J., KORT, H. S. M., DUIJNSTEE, M. S. H., RUTTEN, P. G. S. & HENSEN, J. L. M. 2010a. The indoor environment and the integrated design of homes for older people with dementia. *Building and Environment,* 45**,** 1244-1261.

VAN HOOF, J., KORT, H. S. M., HENSEN, J. L. M., DUIJNSTEE, M. S. H. & RUTTEN, P. G. S. 2010b. Thermal comfort and the integrated design of homes for older people with dementia. *Building and Environment,* 45**,** 358-370.

VAN HOOF, J., AARTS, M. P. J., RENSE, C. G., & SCHOUTENS, A. M. C. (2009). Ambient bright light in dementia: effects on behaviour and circadian rhythmicity.*Building and Environment*, *44*(1), 146-155.

VERNOOIJ-DASSEN, M. Y. R. R. A., FELLING, A., & PERSOON, J. (1997). Predictors of change and continuity in home care for dementia patients.*International journal of geriatric psychiatry*, *12*(6), 671-677.

WATSON, D., & WILLIAMS, J. (2003). Irish National Survey of Housing Quality 2001-2002. *Economic and Social Research Institute (ESRI) Research Series*.

WATERFIELD, P. 2006. *The energy efficient home : a complete guide,* Ramsbury, Crowood.

WHO 2001. *International Classification of Functioning, Disability and Health: ICF*, World Health Organisation.

WHO 2002. *Towards a Common Language for Functioning, Disability and Health: ICF*, World Health
Organisation.

WHO 2010. *WHO - FIC Information Sheet - International Classification of Functioning, Disability and
Health: ICF*, World Health Organisation.

WHO, 2012. *Dementia. A public health priority* [Online] Available:
http://www.who.int/mental_health/publications/dementia_report_2012/en/ [Accessed 30-04-
2014]-

WORKING PARTY ON SERVICES FOR THE ELDERLY (1988), *The Years Ahead – A Policy
for the Elderly*, Government Publications, Dublin.

ZARIT, S. H., & LEITSCH, S. A. 2001. Developing and evaluating community based
intervention programes for Alzheimer's patients and their caregivers. *Aging and Mental Health,
5*(S1), 84-89.

ZARIT, S.H., GAUGLER, J.E., JARROTT, S.E. (1999) 'Useful services for families: Research
findings and directions', *International Journal of Geriatric Psychiatry,* 14: 165-81.

ZEISEL, J. 2006. *Inquiry by design: Environment/behavior/neuroscience in architecture, interiors,
landscape, and planning*. WW Norton & Co.

Appendix 1: Project Steering Committee

National

Mary Connolly, Practice Development Officer, Alzheimer Society of Ireland

Dr Janet Convery, School of Social Work and Social Policy, Trinity College Dublin

Brian Lawlor, Conolly Norman Professor of Old Age Psychiatry at Trinity College Dublin and Director of the Memory Clinic at the Mercer's Institute for Research on Ageing, St James's Hospital

Mary McCarron, Professor of Ageing & Intellectual Disabilities, School of Nursing and Dean of Health Science, Trinity College Dublin

Desmond O'Neill, Professor of Medical Gerontology, Trinity College Dublin and Consultant Geriatrician, Tallaght Hospital

Dr David Robinson, specialist in Medicine for the Elderly, St James's Hospital

International

Joost van Hoof, Head of the Centre for Health Care and Technology (Fontys EGT) at the Fontys University of Applied Sciences, The Netherlands

Appendix 2: Stakeholder Workshop Attendees

Andrea Bobersky	Living with Dementia Programme, TCD
Joan Brangan	Trinity College Dublin
Irene Byrne	Irish Council for Social Housing
Suzanne Cahill	Living with Dementia, TCD / DSIDC, St James's Hospital
Lucy Carey	Irish Planning Institute
Vijoy Chakraborty	Irish Wheelchair Association
Ann Marie Coen	School of Nursing and Human Sciences, DCU
Mary Connolly	Alzheimer Society of Ireland
Janet Convery	Living with Dementia Programme, TCD
Jordan Corrigan	Ageing Well Network
Joanne Coughlan	Stephen Diamond Associates
Ger Craddock	Centre for Excellence in Universal Design at National Disability Authority
Cecilia Craig	DSIDC, St James's Hospital
Mary Deery	Age Friendly County Programme, Louth County Council
John Dennehy	TOTARCH
Gillian Dullea	Health Service Executive
Mark Dyer	TrinityHaus, TCD
Avril Easton	Alzheimer Society of Ireland
Michelle Fagan	Royal Institute of the Architects of Ireland
Joan Fitzpatrick	Health Service Executive
Michael Forrest	Adapt a House
Matthew Gibb	DSIDC, St James's Hospital
Ali Grehan	Dublin City Council
Sinead Grennan	Sonas apc
Tom Grey	TrinityHaus, TCD

Martin Harte	Architect
Shane Hogan	National Disability Authority
Fiona Kelty	National Council for the Blind in Ireland
Mary Lovegrove	Irish Hospice Foundation
Sean Mahon	RIAI/O' Connell Mahon Architects
Michael Mohan	Architect
Maeve Montgomery	Alzheimer society of Ireland, Louth branch
Dolores Murphy	Irish Wheelchair Association
Neil Murphy	Centre for Excellence in Universal Design at National Disability Authority
Nikki Murphy	Scott Tallon Architects
Dearbhla O'Caheny	DSIDC, St James's Hospital
Sandra O'Connell	Royal Institute of the Architects of Ireland
Susan O'Neill	Health Service Executive
Ruth O' Reilly	National Disability Authority
Donie O' Shea	National Disability Authority
Maria Pierce	Living with Dementia Programme, TCD
Lorna Roe	Age Action
Bernadette Ryan	Health Service Executive
Chris Soroghan	Medical Physics, St James's Hospital
Dermod Slevin	Working Group of Persons with Dementia
Pamela Topping	Queen's University Belfast
Stephen Walsh	Irish Planning Institute

Appendix 3 – Scenario A: John living alone in Ballina, Co. Mayo

John - Living alone in a two storey house on the outskirts of Ballina in County Mayo

John is an 85 year old man with mild to moderate dementia. He has been recently widowed and is now living alone in an old two-storey house on the outskirts of Ballina in County Mayo. John is in good physical health and has good mobility, but his hearing has deteriorated. John is well known in the neighbourhood and goes out most days to the shops to buy a paper and other provisions and has no problem with wayfinding. John's neighbours look out for him. His daughter who lives nearby is his main support and calls to see him every day. She has children and grandchildren of her own. John wants to remain living in the house. The family want him to remain there in the community where he is well known and encourage him to go out and about as he has always done. He cooks for himself everyday. His family's main concerns are that he is kept warm and safe while in the house. He lights a fire everyday as he has always done but it may be late in the day before he gets around to doing so. Although the heating is set to come on automatically at certain times, he often changes the settings, and he is regularly found with no heating on in the house. The neighbours often seen on in the house. When his daughter raises these issues with him, he says either that he is 'only up' or that light and heat are expensive and he is trying to save money. His daughter is also extremely worried that someday something, like a fall, will happen while he is in the house alone and she is terrified that she will not be able to get into the house to help him or that he will not be able to get out in the event of a fire. This is her biggest worry.

Consider (i) the adaptations you would make to the house that John currently lives in and (ii) what you would include in the design of a new house which could some day accommodate someone like John.

GROUND FLOOR PLAN 1:50

LIVING — 2900 — 4850
DINING — 3200 — 4850
ENTRANCE HALL
KITCHEN — 990
6250

FIRST FLOOR PLAN 1:50

BEDROOM 1 — 2900 — 4850
BEDROOM 2 — 3200 — 2820
1000
BATH-ROOM — 1910
6250 — 2089

Appendix 4: Scenario B: Mary living with her adult daughter and grandchildren in Dublin

Mary - Recently moved in with her daughter to a 3 storey house in South Dublin
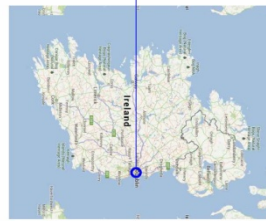
Mary Jones is aged 65 and has early onset dementia (Lewy Body) which has advanced quite rapidly particularly in the last 12 months and she is now disorientated in time, suffers from agnosia (is unable to recognize objects for what they are) and is somewhat withdrawn. She herself is frustrated with the changes dementia has caused to her lifestyle. She also periodically suffers from hallucinations.

Mary was widowed early in life. She worked as a bank teller up until the age of 60 when the symptoms of her dementia began interfering with her work performance and because of this she was asked to take an early retirement.

Mary had been managing reasonably well living alone in the family home - a bungalow in Skerries up until 3 three months ago, when her neighbors started complaining about her behavior (she was leaving the front door wide open at night and playing music at full volume into the early hours of the morning). It was at this stage that Carol her only daughter decided to move her into living with her, in her home on the South side of Dublin.

Carol is separated and works full time. She has three teenage boys each unhappy about their grandmother having moved in their home, since they regularly have to check on her and get her back to bed at night. Their home is three-story large house set on its own grounds in the suburbs of Dublin and Mary's bedroom is in the attic. Since the move, Mary's behavior has worsened considerably. She is constantly wanting to go down to the sea, but where she now lives is a 20 minute drive to a the Killiney sea-front. In the last month, she has had two falls on the stairs, the most recent one being where she misplaced her footing going down the stairs to access the toilet at night. The fall resulted in her fracturing her ribs.

The public health nurse has advised that Carol should probably never have moved her mother to live with her in the first place and that until she recovers, Mary should sleep downstairs on a pull out bed. The public health nurse has also suggested that Carol get an occupational therapist's assessment of both her mother's former home in Skerries (which has not been sold and remains unoccupied) and her own (the three story house) with a view towards making either more dementia-friendly. The public health nurse has suggested that it may be wise for Carol to consider selling her mother's home and building on a granny flat at her own home to offer her mother more ground floor accommodation.
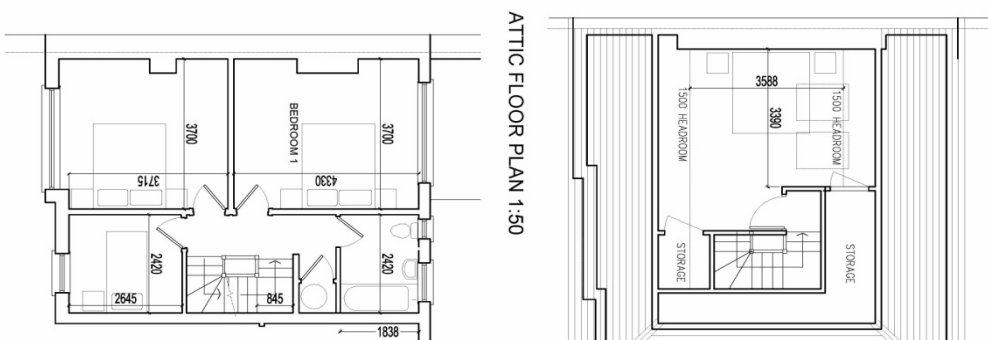
Which of these options do you think at this point in time would work best for Mary Jones?

If Carol chooses to return her mother to her former home, it would have to be modified to make it more suited to her health condition?

If Carol decides to continue to have her mother live with her, what do you think is the best solution regarding these arrangements, modifying the house or building on a granny flat? Give reasons for your answer.
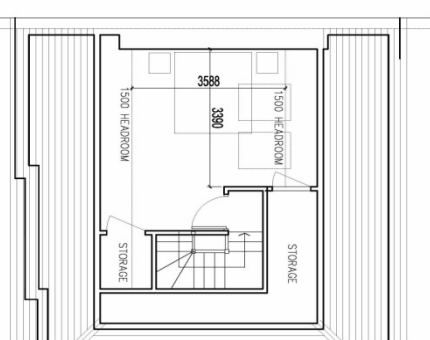
Garden extends 12m from rear wall of house
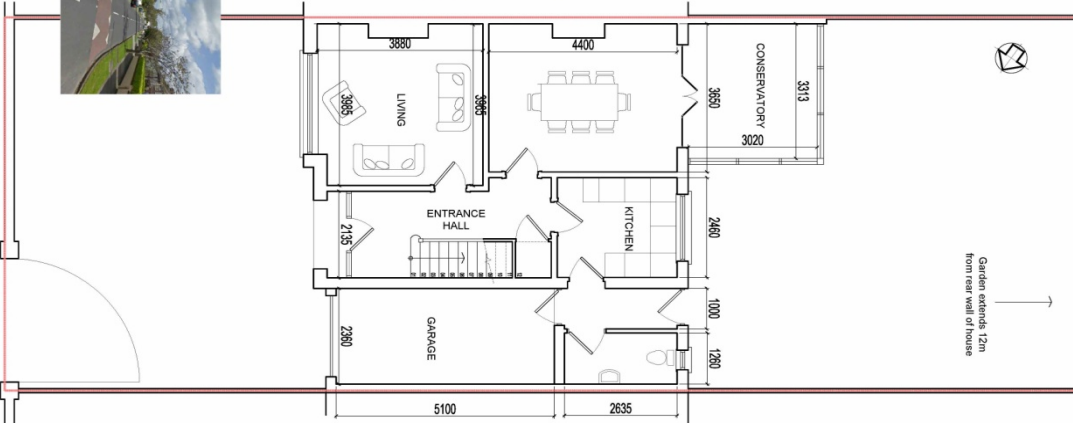
GROUND FLOOR PLAN 1:50

LIVING — 3885

3880 / 4400 / 3985

CONSERVATORY — 3650 / 3313 / 3020

ENTRANCE HALL — 2135

KITCHEN — 2460 / 1000 / 1260

GARAGE — 2360

5100 / 2635

FIRST FLOOR PLAN 1:50

BEDROOM 1 — 3700 / 3700 / 4330 / 3715 / 2420 / 2420 / 2645 / 845 / 1838

ATTIC FLOOR PLAN 1:50

STORAGE / STORAGE

3588 / 3390

1500 HEADROOM / 1500 HEADROOM

Appendix 5 – **Scenario C: Joe & Bridget living in an apartment in Dublin city**
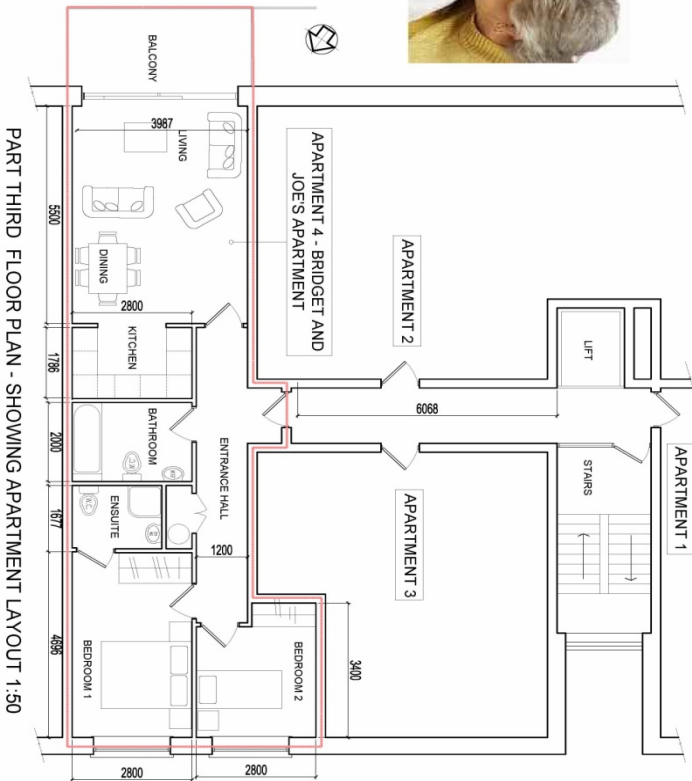

Bridget and Joe - Living in a modern 2 bed apartment in the Dublin Docklands

Following retirement ten years ago, Bridget and Joe decided to sell their four bed-roomed house and move into a new apartment development in the Docklands. The apartment is 65 sq m. Both are now in their mid-70s and Bridget was diagnosed with dementia five years ago. The apartment is located in at the end of a long corridor on the third floor of the development. The entrance to the apartment is poorly lit and Bridget sometimes has difficulty getting out of the glazed entrance lobby and has difficulty using the lift to get to her apartment. She regularly gets lost within the apartment complex and finds it hard to locate the door to her apartment, causing great anxiety to her and Joe. Joe has become so concerned about Bridget losing her way that he is now reluctant to let her go out on her own. Within the apartment, there is a living room, a small kitchen with no natural lighting and two bedrooms. The main bathroom complies with the minimum accessibility standards and there is a smaller ensuite off the main bedroom. In the living room, there are large glass sliding doors leading to a balcony with very nice views over the Docklands, and Joe has locked the doors to the balcony for fear that Bridget might climb on furniture and fall over the balcony. Bridget is constantly trying to open the doors to the balcony and gets very agitated when she can't open them. They are spending more and more time in the apartment and find everyday living quite stressful.

What are the issues that arise in this situation and how can the apartment be adapted to suit the needs of Bridget and Joe. What are the general issues around apartment design and people with dementia?

PART THIRD FLOOR PLAN - SHOWING APARTMENT LAYOUT 1:50

BALCONY

LIVING
3987

DINING

2800

KITCHEN

BATHROOM

ENSUITE

ENTRANCE HALL

BEDROOM 1

BEDROOM 2

3400

2800   2800

5500   1786   2000   1877   4696

1200

APARTMENT 4 - BRIDGET AND JOE'S APARTMENT

APARTMENT 2

APARTMENT 3

APARTMENT 1

LIFT

STAIRS

6068
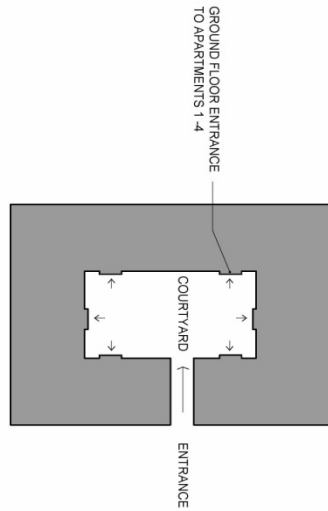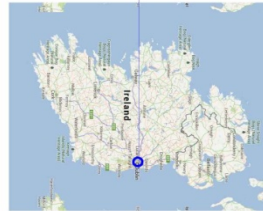
BLOCK PLAN SHOWING GROUND FLOOR ENTRANCE LEVEL 1:500

GROUND FLOOR ENTRANCE TO APARTMENTS 1-4

COURTYARD

ENTRANCE

Client:
CEUD / NDA

Project:
Design Guidance for Dementia & Home Design from a Universal Design Approach

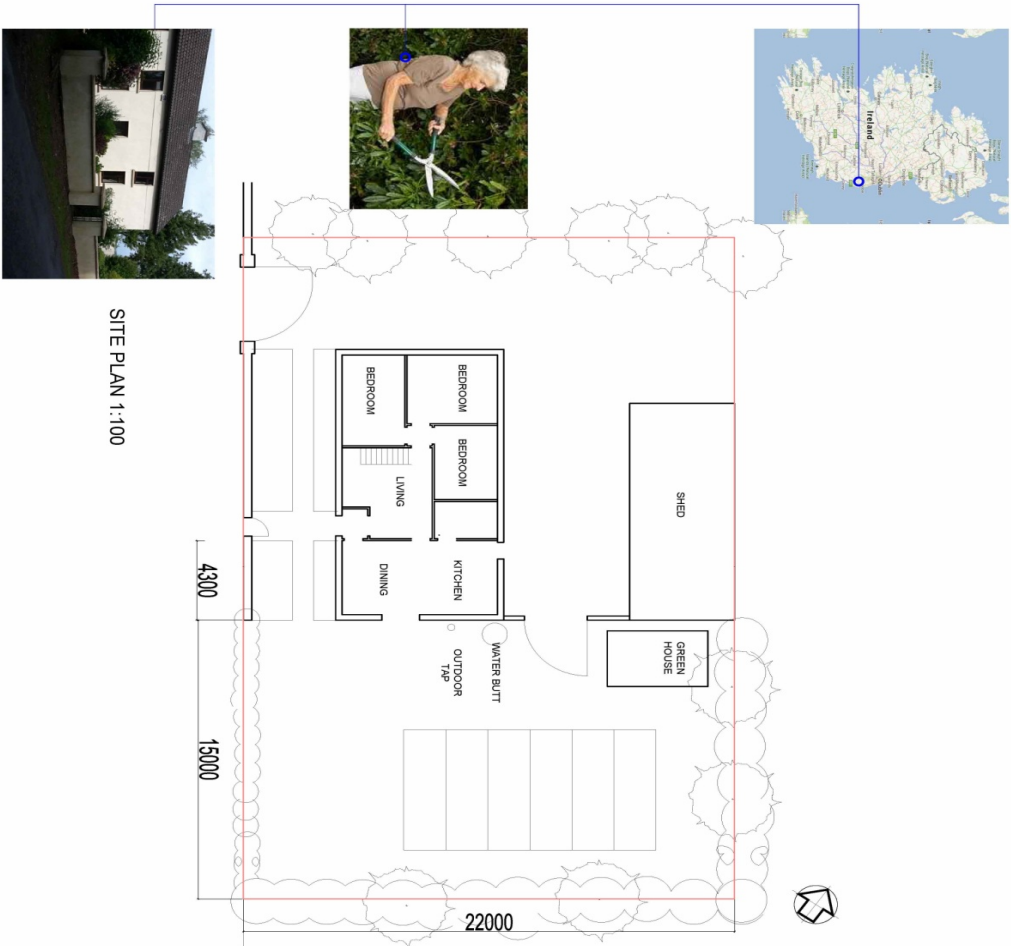Drawing Title:
apartment

Drawn by:

Checked by:

Scale:

Plot Date:

Drawing No:

Rev:

230

Appendix 6 – **Scenario D: Kathleen living alone in a rural cottage in Wicklow**

Kathleen - Living alone in a cottage with a large garden in Wicklow

Kathleen is a recently widowed 84 year old woman who adores gardening. She lives in medium size detached three bedroom cottage within a quarter acre site located towards the centre of a small Irish village. Her cottage garden is located to the side of the property and measures approximately 15 by 22 meters . It is bounded by a hedge and reached by a gravel path over 4 meters long . The front of the cottage has a metal gate and low 600mm high stone wall. The garden has been used for over thirty year to grow vegetables and flowers. The crop of vegetables almost caters for her personal needs whilst also being good enough to exhibit at local agricultural shows. There is a tap for watering plants at the site of the cottage as well as a water butt collecting rainwater from the roof. A small greenhouse is located towards the rear of the garden. Organic vegetable waste is composted for use the following year in the vegetable garden. Since the passing of her husband she has developed the early signs of dementia with loss of memory, forgetfulness, disorientation accompanied by anguish. For her well being she needs to continue gardening but dementia is increasingly causing difficulties.

What are the issues that arise from this situation and could potentially be done to accommodate a person with dementia in this scenario?

SITE PLAN 1:100

BEDROOM
BEDROOM
BEDROOM
LIVING
DINING
KITCHEN
SHED
GREEN HOUSE
WATER BUTT
OUTDOOR TAP

4300
15000
22000