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**Dementia**  
Office

# The Continuum of Care for People with Dementia in Ireland

September 2019



## Report Authorship

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# Foreword

It gives me great pleasure to present this review of long-term care options for people living with dementia in Ireland. There are over 55,000 people living with dementia in Ireland and if trends continue this will increase exponentially in the coming years. The publication of this review is timely in the context of this growing dementia population but also within the broader policy context of the development of the national housing framework for older people.

The Irish National Dementia Strategy crucially outlines the objective that people with dementia should be facilitated and supported to live and die well in their chosen environment including their own home or nursing home if that is their choice. The emphasis on choice and options around care is reflected in this review with a chapter dedicated to the voice of people with dementia. In addition, a range of stakeholders were invited to provide their views on the continuum of care for dementia in Ireland.

At a national policy level there is a commitment for a range of long-term care options designed to comply with best practice architectural principles and staffed by skilled personnel trained to address the complex and unique needs and preferences of people with dementia of all ages (National Dementia Strategy, 2014). The review offers insights into the options being provided to people currently living with dementia in Ireland and provides lessons from abroad in relation to models, costs and outcomes of different long-term care approaches.

I would like to sincerely thank the authors of the report Professor Eamon O'Shea, Dr. Fiona Keogh and Adeline Cooney who were commissioned by the HSE's National Dementia Office to undertake this work. The review addresses one of the actions of the NDS - that the Health Service Executive will examine a range of appropriate long-term care options to accommodate the diverse needs of people with dementia, including those with responsive behaviours. The findings outlined in the review assist the HSE and government departments in future planning, taking appropriate account of potential new residential models, including housing with care and ageing in place.



Michael Fitzgerald

# Executive Summary

## Context

The potential of alternative models of care for people with dementia, including housing with care options, is referenced in the National Dementia Strategy and in the Report on the Review of the Nursing Home Support Scheme (NHSS). The National Dementia Strategy specifically commits the Health Service Executive (HSE) to examine a range of appropriate long-term care options to accommodate the diverse needs of people with dementia in Ireland. In response, the National Dementia Office commissioned this report to provide evidence to support the HSE and the Department of Health to develop appropriate alternatives to the current residential care model for people with dementia in Ireland. The focus, therefore, is on the continuum of care for people with dementia, although many of the observations and recommendations in this report are relevant to older people in general.

## Objectives

- to provide a review of existing long-term care models for people with dementia in Ireland
- to explore the potential of different models in Ireland to meet the preferences and stated outcomes of both citizens and people with dementia
- to provide an overview of innovative models of long-term residential care for people with dementia in other countries
- to provide an overview of international peer-reviewed evidence on the cost effectiveness of alternative long-stay care settings for people with dementia
- to make recommendations for the future development of the continuum of care for people with dementia in Ireland.

## Current Realities

Realistically, for most people with dementia in Ireland, there are only two choices in relation to care setting at the moment - home care or residential/nursing home care. Home care provision is currently under-funded leading to some people with dementia ending up in long-stay care prematurely; home care support services are also unevenly distributed across the country. Family carers bear most of the care burden and financial cost of providing care to older people living with dementia in the community. For example, of the €2 billion costs associated with dementia in the country, almost half are borne directly by informal carers.

When people with dementia in Ireland can no longer live at home, there are very few alternatives outside of residential care settings available to them. Moreover, the current funding system supports the residential care option ahead of all other choices - it is easier to navigate and provides greater certainty in relation to addressing need in times of crisis. The lack of alternative accommodation to traditional residential care contrasts with other European countries where there has been much more innovation and experimentation with regard to housing with care and small-scale living facilities. There are only a very small number of housing with care schemes in Ireland that are capable of addressing the complex needs of people with dementia and none of these are run by a statutory body.

## What Matters for People with Dementia

Living with dementia is a highly individualised and emotional experience. The analysis of various systematic reviews for this report reveals four unifying themes across individuals' lived experience of care in multiple settings: personhood and identity; choice and autonomy; connectivity; and on-going support to live purposeful and meaningful lives. People with dementia want to be valued for who they are; they want to be connected to family and community and they want to live meaningful lives, even if that life is different to the one they had before the onset of dementia. These are the values that must permeate care across the continuum in Ireland. They are not beyond our reach, but the government needs to be more proactive in supporting practical changes through regulation, incentives and funding to enhance autonomy, personhood and connectivity in all care settings.

## Continuum in Ireland

It is increasingly being recognised that age friendly housing is part of the long-term solution to keeping people with dementia living at home for longer. Universal design can help people adapt to change across the life cycle by factoring in key design features at the outset that are flexible and maximise quality of life as the person ages, including being able to respond to issues relating to dementia in later life. Design matters for lifetime housing and equally plays an important role in creating an appropriate and life-enhancing environment of care for people with dementia in all settings.

The family home is the bedrock of care for people with dementia in Ireland and should continue to be supported above all other options. Sometimes, care at home requires adaptation to the family home and government grants are available to support modifications in Ireland. Such support can involve the provision of hoists, bathroom modifications, door widening, lighting, décor and a variety of technological supports. However, the current grant process is overly bureaucratic with considerable lags between the identification of need and the provision of support. Moreover, it is subject to geographical variation, depending on the availability and generosity of local authority budgets. The scheme may, by definition, also react more favourably to physical need than cognitive need and may, therefore, be structurally biased against people with dementia.

Sheltered housing is an alternative to living at home for some older people who are relatively independent and do not need much, if any, supports, except perhaps warden services. Currently, there is no information on the number of people with dementia living in conventional sheltered housing in Ireland, but it is likely to be small given the level of independence required for this form of living arrangement. Housing with care usually involves some form of social housing, which may or may not be dementia specific, supported by a range of community-based care services and supports delivered, on site, to the person with dementia. The key aspect of housing with care is the scale of care provided and the level of integration between that care and the specific housing model. In general, the supported housing framework for people with dementia in Ireland is under-developed, with little innovation and very few demonstration models that might point the way to future development.

The final stage of the continuum covers traditional residential care and nursing home settings. Many long-stay care settings in Ireland are large, mainly to exploit economies of scale, with a small number containing specialised dementia units on site. Stand-alone, small scale living facilities are generally absent, but need to become part of the nursing home of the future in Ireland supporting choice, autonomy and social interactions for people with dementia. Both physical environment and design matter for the well-being of people with dementia.

### **Citizen Preferences**

The evidence is that most citizens want to remain in their own homes for as long as possible and practicable. It is important to remember that fact as we think about planning for the future care of people with dementia and making decisions about new investment along the continuum. We know very little about citizen preferences for care settings should they get dementia; questions about future care arrangements are rarely framed in a dementia-specific way. The little we do know suggests that people want to stay in their own homes, if at all possible, should they become dependent in older age. Older people typically do not think about housing with care options as potential alternatives to living in their own home, mainly because there are so few examples of supported housing schemes in the country. However, citizens have a significant preference for housing with care over nursing homes should they have to move from their current home. They also emphasise the continuing importance of family, community and connectivity to place wherever they live.

### **Lessons from Abroad**

The continuum of care is evolving in Europe, where there has been an increasing engagement and focus on home adaptations, housing with care models and small-scale residential provision in recent decades. That is not to say that the traditional residential model has been usurped, but certainly a recalibration of the care model is taking place, albeit slowly. In France, home adaptation for people with dementia has developed significantly in recent years to fulfil obligations outlined in successive National Alzheimer plans; people with dementia can have their homes assessed for adaptation should that be viewed as beneficial. Small-scale group homes now provide an alternative to the traditional residential care model in Japan. In the Netherlands, residential dementia care has been significantly re-arranged into small-scale independent living facilities. Dementia villages, such as the De Hogeweyk complex near Amsterdam, are also springing up across Europe, providing a counter-institutional protected living environment modelled on a small village, offering a different type of supported-living experience to residents (be: the Hogeweyk care concept, 2018).

### **Quality of the Evidence Base**

The quality of the evidence on dedicated and supported housing arrangements for people with dementia relative to traditional long-stay accommodation is not compelling. The majority of the research is cross sectional and typically does not stretch to longitudinal analysis or economic evaluation. The sheer variety in the type of models now available along the continuum has also created difficulties when comparing the various options, particularly when making comparisons across countries. The vast majority of the available literature in this area is not dementia specific. When studies on people with dementia have been done, the effects on quality of life are promising, but sometimes contradictory, with some studies reporting positive effects on specific health and social domains, while others find no effects on overall quality of life.

The evidence on the economics of care along the continuum is even more inconclusive. There are no definitive studies on the cost effectiveness of various housing with care options for people with dementia relative to traditional residential care models. There are studies on costs, some more comprehensive than others, but few comparative studies. Even when there are cost studies, they are sometimes incomplete. There has been more economic focus on new small-scale residential models relative to the standard institutional model, showing slightly higher costs for smaller-scale models, but very few of these studies have adhered to standard economic practice in relation to evaluation methodology. Policy-makers need good information on both costs and outcomes in order to make good decisions on resource allocation. That information is not currently available in relation to the continuum of care for people with dementia. One practical solution is for the government to incorporate an evaluation framework in any upcoming schemes and demonstrator projects in relation to housing with care for people with dementia in Ireland.

## Stakeholder Views

An important part of the information-gathering for this report involved eliciting the views of key policy and provider stakeholders on the continuum of care for people with dementia in Ireland. A total of 31 stakeholders were contacted to complete a semi-structured questionnaire (See Appendix) comprising ten open-ended questions. The response rate to the questionnaire was 87 per cent, showing a welcome engagement in this issue among key stakeholders.

Stakeholders provided a rich understanding of ageing in place in Ireland that centred on the role of people, communities and the environment in contributing to a good life for people with dementia. Home was the dominant theme among all respondents. The continuum of care is a misnomer for many stakeholders, mainly because of their concern that it may distract from what should be the primary objective of policy, namely to keep people with dementia in their own homes for as long as possible and practicable. Respondents felt that enhanced support for adaptation should be an integral part of any future investment in home care.

Housing with care was identified as a viable alternative to traditional residential care, but people were more circumspect with regard to the concept of the dementia village. Small scale residential care units were preferred over the traditional institutional model, with people favouring individual living units where possible, whereby people with dementia could live relatively independently with access to proximate services and supports as required, including nursing care and end-of-life care as the disease progressed.

When stakeholders talked about barriers to the development of the continuum almost all emphasised the importance of joint action between the Departments of Health and Housing and between the HSE and the various Local Authorities across the country. Joint provision and joint funding models were identified as crucial to the development of new housing initiatives for people with dementia. Stakeholders supported the use of demonstrator projects to showcase the value of co-operation, funded through public-private partnerships and philanthropic support.

Some respondents counselled that ignorance and stigma towards dementia may still permeate housing agencies and care agencies, creating a risk averse, paternal and overly medicalised environment that makes change more difficult than it ought to be. Overcoming that fear and stigma will, according to stakeholders, require continuing positive action in relation to information, incentives, regulation and funding, separately and in combination.

## Principles for Change

Five key principles for the development of policy have been distilled from interviews with key stakeholders and review of the relevant literature: place; personhood; choice; autonomy; and connectivity.

**Place:** Stakeholders were adamant that people with dementia should age in place wherever possible, close to family and community. The movement of people with dementia along the continuum of care should be done sparingly and not at all, if possible. Multiple moves for people with dementia across settings should certainly be avoided. If people have to move, housing and care need to be integrated in a way that allows ageing in place to continue, maintaining attachments and relationships among people and places that enhance quality of life within vibrant age-friendly communities.

**Personhood:** Personhood is already an over-arching principle for the National Dementia Strategy. In relation to the continuum, it should be used to maintain identity and protect the self through an expanded ageing in place strategy. That is mainly achieved by supporting living at home, but if not, it requires the tenets of personhood to be respected and reflected in other settings. That includes respecting the dignity of people with dementia through continuous dialogue and shared decision-making in relation to care setting and care provision.

**Choice:** Choice is the key to optimal provision and resource allocation along the continuum of care for people with dementia in Ireland. Whenever people with dementia are asked about where they want to live, they usually say in their own home. Similarly, when citizens are asked to speculate about where they would prefer to live in their older age, the vast majority say in their own homes. That choice should be respected through public support for universal design, home adaptation and personalised care provision in the home. Some older people may choose to live in supported housing schemes and that choice will also need support through tax incentives and new regulatory procedures that encourage an increased supply of housing with care alternatives.

**Autonomy:** People also want autonomy wherever they live. That means supporting people to live privately and independently, whether they live at home, in supported housing, or in residential care. Many people with dementia can continue to live well in independent settings, supported by care services and supports but not defined by them.

**Connectivity:** Connectivity is also important, meaning that people with dementia should be connected to people, places and communities wherever they live. Once again that is easier when people live at home, but not impossible if they live elsewhere. This has implications for location, proximity, design and staffing in both supported housing and residential care settings. An optimal continuum of care requires the continued engagement of people with dementia in decision-making, discourse and activities, in accordance with preferences and capabilities.

### Policy Recommendations

As people age, their housing needs are likely to change, particularly following a diagnosis of dementia, but every effort must be made to ensure that people remain in their own home for as long as possible and practicable. This can be done through the provision of appropriate levels of personalised home support services and through universal design, sustainable lifetime housing and house adaptation programmes that are timely, accessible and appropriate. For people with dementia who need supported housing with care provision, the principles of personhood, choice, autonomy and connectivity become even more important. Multiple moves across the continuum should be avoided, but if and when long-stay care in residential facilities is required, it should be provided in small-scale, homelike units that preserve the personhood of the resident. The recommendations outlined below are specific to dementia, but complement the recent universal actions proposed by government in their recent Policy Statement on Housing Options for an Ageing Population (Department of Housing, Planning and Environment and Department of Health, 2019).

1. Maintaining people in their own home should continue to be a key goal for people with dementia in Ireland.
2. People with dementia must be involved in decisions around their care. The full commencement elements of the Assisted Decision Making (Capacity) Act 2015 such as the Decision Support Service will provide a legislative underpinning for the necessary support to enable people with dementia to be involved in decision making.
3. People with dementia should not be required to make multiple moves to access different levels of support. As far as is practicable, supports should come to the person, including home support services, assistive technologies and housing adaptations to facilitate ageing in place.
4. Home care should be expanded and enhanced as the key strategy in the development of the continuum of care for people with dementia. The provision of additional personalised services and supports for people with dementia living in their own homes should be prioritised above financial support for any other care setting, especially residential care.

5. Lifetime universal design should become standard for new housing stock, including nursing homes and public long-stay facilities.
6. The home adaptation scheme should be simplified, expanded and managed better for people with dementia. The scheme should incorporate mandatory access to an assessment of the home/living environment for people who have been diagnosed with dementia.
7. Consideration should be given to the development of multi-stakeholder models at Community Health Organisation (CHO) level which integrate the required elements for a timely and tailored response for home adaptations, including health professional assessment, design specialists, budgets, funding approval and contractors.
8. An adequate supply of a range of housing options should be available at a designated geographical level in order to provide for the preferences and needs of people with dementia as they age. For planning purposes this geographical area could be CHO with co-terminus Local Authorities.
9. A number of organisations need to work closely together in order to further develop supported housing options. Structures to enable formal inter-departmental and inter-agency co-operation should be put in place. This cooperation should include joint funding arrangements, and should facilitate enhanced co-operation among health agencies, local authorities, private care providers, housing associations and community and voluntary sector organisations.
10. Demonstrator housing with care schemes for people with dementia should be established to support and test joint financing arrangements and integrated care provision. An evaluation component should be part of any new demonstrator schemes.
11. All new supported housing with care schemes for people with dementia should be built in central locations and embedded within local, inter-generational, communities.
12. Maximum use should be made of assistive technologies to enable people with dementia to remain independent for as long as possible and to enhance their care and quality of life, whatever setting they are in.
13. Dementia villages are only slowly evolving internationally, so further evaluation is necessary before making decisions on any new investment in this type of setting in Ireland. New dementia villages should meet the principles of: place; personhood; choice; autonomy; and connectivity.
14. Following the development of supported housing options and the provision of greater levels of home support services, there is potential in the future for nursing homes to have a far greater focus on the provision of clinical, nursing and end-of-life care.
15. A Continuum Review Group should be established to examine resource use, balance of care, housing infrastructure, dependency, dementia bed capacity and funding requirements across the whole spectrum of care for people with dementia.
16. Future investment in nursing home facilities must incorporate universal design principles and dementia-specific design and should provide small scale, homelike residential living facilities.
17. Funding, incentives and regulatory structures should be adjusted to take account of the realities of growing and developing the continuum of care for people with dementia in Ireland, especially in relation to developing different types and mix of residential provision.

# Chapter 1: Introduction

## Context

The recent *Policy Statement on Housing Options for an Ageing Population* prepared by the Department of Housing, Planning and Local Government and the Department of Health (2019) is indicative of the priority now being given to the development of appropriate housing options for healthy and successful ageing in Ireland. The Policy Statement is underpinned by six principles: ageing in place; using assistive technology; supporting urban renewal; staying socially connected; promoting sustainable lifetime housing; and working together. There are 52 policy actions, many of which reflect the ongoing work of the National Smart Housing Ageing Programme and the Centre for Excellence in Universal Design, both of which aim to maximise the independence, participation and well-being of older people by enabling them to live well in their own home. The Action Plan for Housing and Homelessness: Rebuilding Ireland (Department of Housing, Planning, Community and Local Government, 2016) also notes that older persons have specific housing requirements such as being in proximity to their family and social networks and refers to a new cross-departmental/inter-agency approach, including the development of appropriate pilot projects by Local Authorities. At its core, the Policy Statement reflects a desire to keep older people at home and develop new housing models, all the time supporting their autonomy and connectivity within supported living environments.

The need to take account of potential new residential models for people with dementia, including housing with care is referenced in the National Dementia Strategy and in the report on the review of the Nursing Home Support Scheme (Department of Health, 2015). The National Dementia Strategy commits the Health Service Executive (HSE) to examine a range of appropriate long-term care options to accommodate the diverse needs of people with dementia in Ireland. In response, the National Dementia Office commissioned this report to provide evidence to support the HSE to develop appropriate alternatives to the current residential care model for people with dementia into the future.

## Objectives of the Report

The focus of this report is explicitly on the continuum of care for people with dementia. In that respect, it is different to the recent joint policy statement the Department of Housing, Planning and Local Government and the Department of Health (2019) which, by definition, is much broader and contains no direct reference to dementia or Alzheimer's disease. However, the report should also be seen as complementary to the joint policy statement, supporting, as it does, ageing in place, sustainable lifetime housing, social connectivity and new housing with care models for older people. The specific objectives of the report are as follows:

- to provide a review of existing long-term care models for people with dementia in Ireland
- to explore the potential of different models in Ireland to meet the preferences and stated outcomes of both citizens and people with dementia
- to provide an overview of innovative models of long-term residential care for people with dementia in other countries
- to provide a review of international peer-reviewed evidence on the cost effectiveness and impact of alternative long-stay care settings for people with dementia
- to make recommendations for the development of the continuum of care for people with dementia in Ireland.

## Ageing in Place

The National Positive Ageing Strategy (Department of Health, 2014), set out a vision for ageing in Ireland that emphasised ‘ageing in place’ as one of its key goals. While the phrase ‘ageing in place’ has been readily adopted since by policy-makers, the term ageing is probably better understood than place. The latter is most readily associated with location which, in turn, is mostly understood in terms of attachment and belonging (Rowles, 1983). But the landscapes of place are many and complex, consisting of real and imagined memories, heavily influenced by the deeply interwoven influences of time and space (Kearns and Coleman, 2017). In recent years, there has been much focus on people’s personal place identification, including new ideas to support ageing in place, such as smart homes, ambient-assisted-living design and universal design (Rowles, 2017). This has led to national and international support for creating age-friendly communities, stimulated by a World Health Organisation age friendly cities initiative in 2007. Older people are among those who are benefiting most from these initiatives, including people with dementia. The current international policy focus, evident in many countries, of keeping people with dementia living in their own homes for as long as possible and practicable, is related to an ageing in place philosophy that sees home as the keeper of memories, associations and connections, which on their own and in combination are central to well-being and quality of life.

The family home is the primary setting for people with dementia in Ireland. Families usually provide the vast bulk of care to people with dementia and ageing in place would not be possible without family carers. However, the commitment to home care may not always be possible for a variety of reasons, including formal care budget constraints, carer burnout and concerns about the quality of care relative to need. The finely balanced home care model can equally be thrown out of equilibrium if people with dementia live on their own, have complex co-morbidities or are isolated socially. One of the problems in Ireland is that should home care be impossible for one reason or another, the only alternative is residential care, either publically or privately provided. Not only can residential care be an expensive alternative, but it can also truncate ageing in place in an abrupt and often brutal fashion.

## Continuum of Care

In Ireland, few real alternatives exist for people living with dementia who want to continue to live independently as the disease progresses, outside of traditional long-stay care facilities (O’Shea et al, 2017). Figure 1 shows the potential variety in the continuum of care for older people ranging from mainstream housing to care in long-stay facilities. Sometimes supporting people with dementia at home requires adaptation to the family home and government grants are available to support modifications, although the process has often been criticised as slow, unwieldy and cumbersome (ALONE, 2018). Sheltered housing is the most common form of alternative accommodation for older people in Ireland, but, as currently interpreted and provided, it does not specifically target people with dementia. Sheltered housing caters mainly for older people who are relatively independent and do not require much in the way of services and supports. The key discriminant as one moves along the supported housing part of the continuum is the range and depth of services and supports available to the person to allow them live independently, often referred to as housing with care solutions.

Figure 1: Continuum of Care



There has been little provision of housing with care for people with dementia in Ireland; the Anam Cara facility in Dublin is one of the few housing with care models that specifically caters for people with dementia. Dementia villages are also rare in Ireland and the Carebright village in Bruff is the only example of this type of care. Small-scale, independent residential living communities offer an alternative to traditional nursing-home facilities and have been adopted in some countries. These arrangements usually comprise of living environments where people with dementia share a home with other residents and staff. Such arrangements are intended to facilitate autonomous communal living and social engagement more than traditional nursing home arrangements, with a view to improving residents' quality of life and providing them with more independence than in traditional facilities. This person-centred approach expands the focus beyond clinical care to meeting the social and emotional needs of people living with dementia.

Accommodation in innovative facilities, including small-scale living communities, multi-generational homes and dementia villages are slowly developing internationally, particularly in the Netherlands and increasingly in Japan. In Ireland, the role of the continuum and its potential to make a major contribution to the quality of life of people with dementia is yet to be fully recognised. Ireland has been especially slow to develop housing with care alternatives to residential care for people with dementia. Similarly, while very few countries have managed to transition the majority of their residential care services to smaller, home-like, non-residential care models, most dependent older people in Ireland, especially those with dementia, reside in more traditional long-stay facilities if they can no longer live at home or in supported housing alternatives.

### Meaning of Housing

Before progressing to an exploration of the continuum of care for people with dementia in Ireland, we include, in full, the transcript of a powerful blog by the dementia activist and person with dementia Wendy Mitchell from the UK, on what housing means to her and the importance of ageing in place. It provides direct experience of what matters for people with dementia in relation to housing and had a profound influence on our thinking and subsequent narrative for this report.

*Hello, it's Wendy, so what does the right housing mean to me? Well first and foremost it has to be my house. I haven't lived with anyone for many years so the thought of other people in my house or living with others is not an option for me. I've always been very independent and found ways round problems and I'm still doing that now in fighting the challenges dementia throws at me. I don't want to be in a care home ever, so my house is my haven, but what me and my daughters didn't realise when I chose the village house was the fact I wasn't capable of choosing an appropriate house anymore. I chose it because I liked the big windows overlooking the paddock. I never considered the steps, the garden and many other inappropriate things, but we are where we are so I have to make the most of what I've got and make things work for me through adapting. One of the first things to go were in the kitchen. It used to have two doors which really confused me, as closed doors means nothing to me as I can't remember where they lead, my solution was simply to remove the doors so the stress has gone as I can see where each door leads. I don't see my wardrobes and kitchen cupboards as they blend into walls. My solution to that was to take photos of the contents and stick them on each cupboard. It's the photos that attract my attention rather than the actual contents of the photo. Light switches are also a problem as they are nearly always white and so can also blend into the wall so I simply painted a dark blue border around each of them so now I have no problem finding the light switches as that can be very stressful. As for the steps leading up to my house and garden, I was forever falling up or down them as wouldn't see them so now I've painted a luminous yellow stripe up each and haven't fallen since. My neighbours help me by taking my dustbin down the steps if they see I haven't been able to and the dustbin men bring them back to the steps instead of leaving them with all the others on the road. Just simple acts of kindness, they can go*

*such a long way. There are so many other simple cheap solutions in the house, the letter T on the toilet doors, the simple on, off, hot, cold labels I've put on the shower, the forget-me not tiles outside my front door for when I forget which house is mine. I also don't have mirrors in the house as I found the sudden sight of someone startled me because I live alone. I treat dementia as a game, it throws me a challenge and I solve it to try and keep one step ahead. As I said, my house is not ideal and I'm sure I'll make and have many more adaptations but that's what dementia is all about, a life of adapting.*

Wendy Mitchell's articulation of the importance of her own home is a cautionary tale and one that informs the remainder of this report. Removing someone from their own home should be a last resort, only done when no other solution is available. That is why home care, universal design and home adaptation matter so much and should take priority in any resource allocation decision-making along the continuum of care. Design and adaptation should be integrated into home care packages for people with dementia, given equal status alongside care hours or psychosocial provision. Housing with care should incorporate own housing with care, as much as group housing with care. The focus should be on providing personalised supports to people with dementia living in their own homes in their own communities.

### **Report Plan**

Following the introduction, the review begins in Chapter 2 with a summary of the demography of need in relation to dementia care in Ireland. Chapter 3 addresses current policy, which can be characterised as a straight-forward choice between home care and traditional residential care/nursing home care for people with dementia. This is followed in Chapter 4 by a review of the relevant literature on what people with dementia want from care providers, irrespective of care setting. The nascent continuum of care for people with dementia in Ireland is presented in Chapter 5. Citizens's preferences for different care settings are reviewed in Chapter 6. Chapter 7 distills lessons from abroad in relation to the breadth and depth of the continuum for people with dementia, including consideration of some of the economic evidence in relation to the cost effectiveness of care in various settings. The views of Irish stakeholders are considered in Chapter 8 on a whole range of issues pertaining to the continuum. Chapter 9 puts forward proposals for the development of the continuum in Ireland, including policy recommendations that may be helpful to decision-makers. A brief conclusion is presented in Chapter 10.

## Chapter 2: The Demography of Need

### Introduction

Ireland's population in 2016 stood at 4,757,976, of whom 637,567 people were aged 65 years and over. We can state these figures with confidence, as they are taken directly from the Census of Population (Central Statistics Office, 2017). Estimating the number of people with dementia is less straightforward, as the Census cannot directly provide us with such a figure. This is where epidemiological studies come into play. There are no Irish epidemiological studies to inform estimates of the prevalence of dementia in Ireland, a situation similar to many other European countries (Kiejna et al., 2010, Misiak et al., 2013). This is not surprising as epidemiological studies are costly, complex and time consuming to undertake (Gordon et al., 1997). This chapter provides estimates of the number of people with dementia in Ireland, based on the most recent CSO 2016 Census, using international epidemiological studies as proxies for Irish prevalence and incidence rates. It also reflects on future capacity requirements that may be needed to meet the increase in demand arising from demographic changes in the older population.

### Overall Population Growth

Ireland has a relatively low proportion of population aged 65 years and over, at just under 14%, compared to other comparator countries (OECD, 2014; Department of Health, 2018). For example, Sweden and Denmark have around 20% of their population aged 65 years and over, while Japan has 25% of their population aged 65 years and over. Ireland's position is changing however, as it catches up on other countries in terms of the ageing of the population. It is likely that the impact of future demographic ageing on resource allocation and capacity requirements will be keenly felt in the coming decades, relative to other European countries especially.

**Table 2.1: Current and Forecasted Age Structure of the Irish Population**

Age Band	2016	2031	Change 2031 (1000's)	Change 2031 %
0-1	62	53	-9	-15
1-6	414	301	-113	-27
7-15	590	571	-19	-3
16-44	1,915	1,999	84	4
45-64	1,128	1,377	249	22
65-74	368	526	158	43
75-84	195	343	148	76
85+	67	131	64	96
Total	4,740	5,301	561	12

Overall population growth in Ireland is currently forecast to be, on average, 0.75% per year up to the year 2031, leading to an overall growth of 12% over the period until then. The composition of the expected population growth up to 2031 is worth noting (Table 2.1). There will be a decline in the early age cohorts, specifically up to fifteen years of age. However, growth in the age cohorts aged 65 and over will be particularly strong. Each of the three over 65s age cohorts 65-74, 75-84 and 85+ will show strong absolute and relative increases up to 2031. The absolute number of people in the 85+ age category will almost double in the next fifteen years. Growth in the 65-74 age category will be 43%, while the 75-84 age cohort will increase by 76%. This level of expansion in the very older population will have particular relevance for dementia, given the relationship between age and the onset of the disease.

### Dementia Population in Ireland

In the absence of national prevalence studies of dementia, the number of people in Ireland with dementia can be estimated by applying the age and gender adjusted prevalence rates from international studies to Irish population data from the 2016 Census (CSO, 2017). The EuroCoDe prevalence rates, which have historically been used to generate prevalence estimates for Ireland, are based on a meta-analysis of 17 European studies published between 1993 and 2007 (Alzheimer Europe, 2009). An alternative to the EuroCoDe approach are the CFAS longitudinal studies in the UK which are high quality, large scale, longitudinal studies specifically designed to detect changes in prevalence rates over time (Matthews et al. 2013; Matthews et al., 2016). A further set of prevalence rates are available from a Delphi consensus on estimated prevalence rates for people with dementia in the UK (Prince et al., 2014).

**Table 2.2: Prevalence rates (%) and Estimates for Number of People with Dementia in Ireland.**

Age Category	EuroCoDe	CFAS I	CFAS II	UK AS Delphi
60-64 years	0.5	-	-9	-15
65-69 years	1.6	1.8	-113	-27
70-74 years	3.6	2.6	-19	-3
75-79 years	7.3	6.6	84	4
80-84 years	15.6	14.2	249	22
85-89 years	25.9	24.2	158	43
90+ years	40.2	41.8	148	76
<b>Number of People with Dementia</b>				
30-59 years	2,992	-	-	756
60-64 years	1,319	-	-	2,150
65+ years	50,956	47,588	36,366	39,841
<b>Total with Dementia</b>	<b>55,266</b>	<b>50,494</b>	<b>39,272</b>	<b>42,747</b>

Source: O'Shea et al (2017)

Depending on the prevalence rates used, the estimated number of people in Ireland with dementia in 2016 ranges from 39,272 to 55,266 (Table 2). The most commonly used estimate for the number of people with dementia in Ireland, based on the application of EuroCoDe prevalence rates to CSO population data, is 55,266 (O'Shea et al., 2017). However, if we apply prevalence rates from the two waves of the Cognitive Function and Ageing Study (CFAS) in the UK (Matthews et al., 2013; Matthews et al., 2016) the number of people with dementia in Ireland is lower, ranging between 39,272 and 50,494 people. Applying prevalence rates generated through the UK-based Delphi consensus process suggests that the estimated number of people with dementia in Ireland is 42,747. The uncertainty surrounding prevalence does not make it easy to plan services and supports now or in the future. That should be borne in mind as we tease out some of the implications of these numbers for investment along the dementia continuum.

## Functional Disability and Dementia

Pierse et al, (2018) have estimated that there are 19,530 people living in nursing homes with dementia in Ireland, most of whom have high levels of functional impairment. Subtracting the number of people in residential care with dementia from the most commonly used EuroCoDe-based estimate of the total number of people with dementia, suggests that the number of people living at home in the community with dementia in Ireland is 35,736. Of those people living at home, 15,508 are likely to have low to moderate functional disability, 16,832 most likely have severe functional disability and the remainder are chair/bedbound.

People with dementia need different supports depending on their circumstances and the stage of the disease. For example, people in the early stages of dementia require timely diagnosis, information and emotional support (Stokes et al., 2014 Manthorpe et al., 2011). As the disease progresses, cognitive and functional capacity decline and behavioural symptoms can become more pronounced, resulting in increased care needs and increased risk of nursing home admission (Garre-Olmo et al., 2014 Toot et al., 2016). The provision and location of care is very much influenced by the functional, emotional and behavioural needs of people with dementia as the disease progresses. Of course, through reverse causation, the continuum of care can also influence the aetiology and progression of the disease over time.

Keeping people living in their own home is the primary objective of policy for people with dementia in Ireland. But not everyone with dementia can continue to live in their own home. Alternative placement for these people that does not involve admission to conventional residential care facilities, public or private, has been neglected in Irish public policy. This is now changing as policy-makers seek to widen and deepen the continuum of care for people with dementia to including a range of potential options, particularly supported housing with care. The search for alternatives is not only to potentially reduce the overall cost of care, but to allow greater choice for people with dementia as the disease progresses and care needs become more complex.

## Future Projections of Dementia Population

There is some urgency in relation to the development of the continuum given the demographic changes soon to affect Ireland. The application of EuroCoDe prevalence rates to the most recently available population projections from the CSO (2017) suggests that there will be a sustained increase in the number of people with dementia in Ireland over the next thirty years (Table 2.3). The number of people with dementia is expected to grow at an average rate of 3.6 per cent per year over the next three decades, putting considerable pressure on existing services and supports. By 2036, the number of people with dementia in the country will have doubled; within thirty years from now in 2046, the number will have almost trebled to an estimated 157,883 people.

**Table 2.3 Projected Growth in the Number of people with Dementia in Ireland by Age Group, 2016-2041 (M2F1)**

Age Group	2016	2021	2026	2031	2036	2041	2046
30-59	2,992	2,933	2,871	2,854	2,847	2,879	2,991
60-64	1,319	1,449	1,615	1,738	1,905	2,044	1,896
65-69	3,377	3,681	4,108	4,586	4,986	5,438	5,774
70-74	5,689	6,842	7,575	8,518	9,543	10,395	11,381
75-79	8,451	10,206	12,564	14,055	15,925	17,971	19,693
80-84	12,621	14,015	17,861	22,348	25,375	29,104	33,195
85+	20,817	26,514	32,427	41,764	54,845	68,632	82,953
<b>Total</b>	<b>55,266</b>	<b>65,641</b>	<b>79,021</b>	<b>95,863</b>	<b>115,426</b>	<b>136,462</b>	<b>157,883</b>

Source: O'Shea et al (2017)

## Capacity Requirements

The growth in the numbers of people with dementia will have implications for service provision at all levels, within community-based care and residential care facilities. Unfortunately, there has been no work published on estimating the effects of the impending growth in dementia numbers for resource use and resource allocation in Ireland. There have been estimates made of the increase in capacity required as a result of the general ageing of the population (PA Consulting, 2018). Those estimates show that, with no service reconfiguration, there will need to be an increase of 10,100 long-stay beds between 2016 and 2031, an increase of 39 per cent. (Table 2.4). Similarly, with no service reconfiguration, home care packages will need to increase by 70 per cent, intensive home care packages similarly, but from a much lower base, and home help hours by 69 per cent.

**Table 2.4: Capacity Requirements with no Services Reconfiguration**

Setting and Service	2016	2031	% Change
Long-stay beds	26,200	36,300	39%
Home care packages	15,600	26,600	70%
Intensive home care packages	200	330	70%
Home help hours	10.6 million	17.8 million	69%

Source: PA Consulting, 2018

A number of different change scenarios have been considered by the Department of Health that might influence future capacity requirements, one of which involved an improved model of care centred on an expansion of community-based services (PA Consulting, 2018). For example, a 30% increase in home care was modelled, as was a 20% increase in public health nurse activity. There was no reference, however, in either the baseline estimate or reform scenarios to the potential of developing the continuum of care in terms of building and supporting alternative forms of accommodation for older people between home care and residential care, either generically or specifically for people with dementia.

**Table 2.5: Housing Requirements for Older People - 10 Year Indicative Forecast**

Type of Housing	10-year Indicative Requirements
Home adaptation	€845m investment
Shared housing in the community	16,307 new units
Supported housing	45,905 new units
Nursing home	13,000 additional beds

Source: ALONE, 2018

In a recent report on housing choices for older people ALONE (2018) reflected on the requirements for different types of housing for older people over the next ten years. The organisation called for a spectrum of housing that facilitated choice and income levels among potential occupants. They highlighted the importance of the expansion of community-based supports to allow people to remain living in different types of housing in the community. Although ALONE estimates of future housing requirements are not dementia specific, they are the only available pointer to future indicative needs along the care continuum (Table 2.5). ALONE call for a major investment in home adaptation grants amounting to €845m over the next ten years. They also recommend additional purpose built homes within existing communities, built to age-friendly and Universal Design principles, supplemented by 16,307 shared-housing schemes. Their indicative requirements for supported housing schemes over the next ten years is 45,905, the majority of which will not require access to onsite services and supports; only 4,341 of these housing units will require care support staff who are permanently based on the site. ALONE also forecast the need for an additional 13,000 nursing home beds over the next ten years, based on current occupancy rates. There is no breakdown of how many of these beds will be occupied by people with dementia.

## **Conclusion**

Estimates of the number of people with dementia in Ireland vary, but the most commonly used figure is 55,000 people. About 35,000 of those people live at home in the community. When we speak about the continuum of care, it is largely this group that are of interest, mainly in terms of their suitability for alternative forms of housing accommodation, should they ever need to leave their own home. We have very little evidence to guide us when deliberating on changes to the continuum of care for people with dementia in the future. There was no mention of developing supported housing models, either generically or specifically for people with dementia, in the recent Health Service Capacity Review published by the Department of Health. All we have to guide us are indicative housing requirements developed by ALONE, none of which are dementia specific. This makes resource allocation decision-making on the continuum of care for dementia very difficult. There is little firm evidence to guide us in relation to demand and, even if there were, the supply-side remain fragmented and incomplete. This applies equally to the residential care/nursing home sector where traditional large-scale models dominate any attempts to develop small-scale living facilities for people with dementia.

## Chapter 3: Current Realities

### Introduction

Providing care to enable dependent older people to remain at home has been the policy objective in Ireland for many years. That policy has, however, not been very successful. Home care services are fragmented, underdeveloped and underfunded compared to residential care (O'Shea et al, 2017). The paucity of home care provision also puts pressure on acute hospitals. Demand for publicly funded home care services is, therefore, greater than the level of services that are available. Given the expected rise in the number of people with dementia in the next twenty years, demand is set to increase significantly in the near future. Housing with care currently plays a very small role in meeting the needs of people with dementia in the community. The choice facing most people is between care in their own homes and admission to residential care/nursing home beds. That may even exaggerate the available choice, because many people with dementia do not access any services at all and, therefore, do not show up on any part of the continuum of care.

One of the enduring criticisms of government policy for dependent older people in Ireland is the imbalance in public spending between residential care and community-based care. Currently, the government is spending more than twice as much on residential care through the Nursing Home Subvention Scheme (NHSS), the so-called Fair Deal Scheme, than on community-based care for people with dementia. Historically, even when public resources were plentiful, investment in community-based care was relatively poor (O'Shea and Carney, 2016). When budgets are curtailed, as happened in recent times, there is limited scope as to where these cuts can fall, due to two major constraints: the need to continue providing services that are mandated or have a legislative basis (as you can be brought to account if they are not provided); and the high level of fixed pay costs in the system. The only statutory scheme we have in place at present to care for older people is the Fair Deal scheme, so there is an element of protection in the residential sector compared to home care provision, where there is no statutory protection. Fixed staff costs also affects decision-making in relation to cuts. These constraints mean that if cuts are necessary, they tend to fall on what is termed 'discretionary' spending e.g. services that do not have a legislative underpinning. This is why home care is often one of the first targets in times of adversity, even though most people know that this is counter-productive in the long-term.

### Community-Based Care

Community care service provision is based on a budget constrained, supply-driven model, partly due to the absence of a legal basis for many services, with provision determined more by the needs of the provider than the needs of the older person. The paradox is that the more successful Fair Deal is in funding highly dependent older people, the more important it is that community care services are expanded to meet the needs of those who remain living in their own homes. The most important part of the care jigsaw, therefore, is investment in community care, which has always been residual to residential care in Ireland. It is no surprise, therefore, that the Government are now taking steps to develop a statutory response to deficiencies in this area, through a new Home Care scheme with a statutory basis. One of the resounding weaknesses of home care provision in Ireland compared with those developed and delivered in other countries (such as the UK, Norway, Sweden, Denmark, France and Australia) is that services for people living at home are not underpinned by legislation. However, moving from the current fragmented system of community-based care to a rights-based model will take time and will be expensive to achieve. There is significant un-met need in the community that will draw heavily on the Exchequer following the implementation of a rights-based approach.

In Ireland, the Home Support service is a very important community-based resource for dependent older people living at home. The Home Support service (which combines the formerly separate Home Help service and the Home Care Package scheme) aims to support older people to remain in their own homes for as long as possible and to support informal carers. Home Support provides help with everyday tasks including: getting in and out of bed; dressing and undressing; and personal care such as showering and shaving. The support provided depends on the individual needs of clients and care can be provided by the HSE or by an external provider, approved by the HSE. The most recent data from the Health Service Executive (2018) shows that 17,094,000 million hours of Home Support were provided to 50,500 recipients in 2017, suggesting that the average number of hours per client was 6.5 hours per week. There is no data on how many of recipients had a diagnosis of dementia.

In 2014, the HSE funded intensive home care packages for people with dementia known as Dementia-IHCPs. The aim of this initiative was: to provide a greater range and level of services to older people with complex needs and their families; to tailor home care delivery directly to the needs of recipients; and to help address the pressures on acute hospitals. The initiative formed part of the implementation of the National Dementia Strategy (NDS). Keogh et al., (2018a; 2018b) estimated that the average weekly cost of a Dementia-IHCP is €925. This is significantly less than the average weekly cost of an acute care bed (circa €5,992). The weekly cost of Dementia-IHCPs for the exchequer is also cheaper than Dublin nursing home costs (€1,149) and public long-stay care costs (€1,526), while it is broadly similar to non-Dublin nursing home costs (€909). However, adding informal care costs to the exchequer costs raises the overall cost of home care relative to residential care, even more so if private out-of-pocket expenditure on home care is included.

The Dementia-IHCP initiative indicates that investment by the HSE in home care packages can keep people living at home for longer, including people with significant levels of disability and cognitive impairment (Keogh et al, 2018b). However, the rolling out of the Dementia-IHCP initiative has been conservative, influenced by enduring budget constraints and the relatively high cost of care, at least relative to conventional spending on community care. The Health Service Capacity Review (Department of Health/PA Consulting Group, 2018) reported that there were 200 packages in 2016, the vast majority of which were for people with dementia; the recommendation from the Capacity Review was that the number of packages should rise to 330 by 2031. While recent evaluations of Genio-funded demonstrator programmes have highlighted the advantages of a more community-oriented, personalised approach (O'Shea and Murphy, 2014; O'Shea and Monaghan, 2015; O'Shea and Monaghan, 2017), it will take time for the overall culture to change in relation to home care provision for people with dementia. There is a genuine commitment to change, but some structural inertias need to be overcome in the way that care is delivered. Slaintecare may accelerate progress towards a new model of community-based care for people with dementia.

### **Residential Care**

We have seen in the previous chapter that there are about 20,000 people with dementia living in residential care/nursing home facilities, comprising approximately 70 per cent of the total residents. We have no estimate of how many people with dementia could have been kept out of residential care if the continuum of care had been better developed. We do know, however, that quality of life for older people resident in long-stay care in Ireland is not always what it should be (Murphy et al, 2006; Cahill et al, 2012; O'Shea et al, 2017).

The vast majority of people with dementia in Ireland living in residential care are still cared for within generic care facilities for older people, most of which are not purpose-built for dementia and many of which are not designed to cater for the complex, challenging and unique needs of residents with dementia. For front line care workers, this makes the task of providing care very difficult, especially when residents with dementia are likely to require more personalised care and attention. There have been concerns about the use of antipsychotic medication, physical

restraints and surveillance technologies in residential care facilities that, on their own or in combination, may be intrusive, restrictive, unethical and disempowering (Astell, 2006; Hofmann and Hahn, 2013).

People with dementia are particularly sensitive to their environment and good environmental design is now widely regarded as critical to the care of people with dementia. Indeed, some people have argued that design is as vital to resident care as nursing care or the approach to the organisation of care within a facility (Fleming and Purandare, 2010). People with dementia should also be connected to, and engaged with, the outside world. Therefore, segregated and remote nursing home care can never be justified and for some people may constitute a denial of the human rights of residents (Ilinca et al, 2015). Very few long-stay facilities are currently integrated into community life, leading to a disconnect between residents and neighbourhoods and a weakening of ageing in place. Given the importance of connectivity for personhood within dementia, new ways of reaching into and out of long-stay settings are necessary.

In recognition of the special needs of people with dementia in residential care settings, the trend in many countries nowadays is towards providing specialist care in creatively designed small-scale units (Cahill et al., 2015). While some dedicated dementia-specific beds are available in public long-stay facilities in Ireland, these are still the exception rather than the rule. Very few people with dementia (about 11%) gain access to specialist care units (SCUs) and even when they do, the size of these units does not always conform with best practice models. Moreover, there is no standard definition of what constitutes an SCU in Ireland, nor indeed is there an agreed meaning or definition for the term 'dementia specific bed' within a generic facility. The availability of reliable data on the location and quality of SCUs is all the more urgent given the significant concerns about the lack of good quality, dementia-specific-long-term-care facilities expressed by participants at the 2011 National Dementia Summit (Alzheimer Society of Ireland, 2011).

The care process within long-stay facilities is also important in allowing residents to live well with dementia. There is no doubt that the medical and functional needs of residents continues to dominate the care landscape within residential care settings. While this is understandable, psychosocial approaches are also needed to complement medical and neurological models of service delivery. However, with a few exceptions, psychosocial provision is largely absent in residential care settings in Ireland. Even where it does exist, it is residual in nature, included almost by way of an after-thought and often, as in the case of reminiscence, conducted by staff with no specialist expertise or training in the area (Parsons et al., 2015). This is regrettable because psychosocial interventions can assist in developing meaningful communication with patients, using all of the senses, through reminiscence, music, art, dance and various therapeutic and time-intensive activities. This emphasises again the need to regulate for personhood and person-centred care for people with dementia. The practice of personhood is not fully reflected in current inspections and reports on nursing home provision in Ireland.

### **New Thinking**

Fixing the social care system for people with dementia should be about more than simply expanding home care packages, helpful and all as that might be for some people. It requires a change in ideology, in how we think about and talk about dementia and in how we view those who experience the symptoms of the disease and in how services are developed and delivered (Hughes, 2011, 2014). Instead of focusing on the person diagnosed with dementia as a 'patient' 'client', or 'target of care', it is crucial to see the individual as independent and an 'agent' of his or her own life who must be encouraged and supported to live a good life and one meaningful to him or her (Lindemann, 2014). Consequently real change needs to encompass support for independent living incorporating a whole range of services that are of value to the person with dementia and promote that person's dignity and personhood. Moreover, it is not enough to talk about the principles of personhood and citizenship and have words like person-centred care enshrined in care plans, they must also be regulated for if they are to become

central to the care system. The current regulatory system of care for people with dementia is not sufficiently rooted in personhood or citizenship rights despite both being fundamental principles underpinning the National Dementia Strategy. Bridging the gap between the rhetoric of public policy on dementia and the reality of everyday practice needs to be urgently addressed.

### **Conclusion**

People's choices need to be respected and reflected in dementia care in Ireland. Autonomy begins and ends with allowing people to remain in their own home for as long as possible and practicable. That is what people say they want, so policy should be directed first and foremost to ensuring that happens. It is only when all own home care options are exhausted, including adaptation, that we should begin to think about other options along the continuum of care. Compared with other countries, there are very few alternatives outside of traditional residential care/nursing home settings available to people living with dementia who can no longer live in their own home. Only a very small number of housing with care schemes exist for people with dementia and none of these are run by a statutory body. Moreover, the current funding system supports the residential care option ahead of all other choices, including home care - it is easier to control and provides greater certainty in relation to addressing need in times of crisis. The Irish National Dementia Strategy (Dept. of Health, 2014) refers to the need for a 'range of long term care options designed to comply with best practice and architectural principles' (p 24). Providing alternatives for people with dementia who can no longer live at home should certainly be prioritised and is long overdue. The remainder of the report is focused on how this can be achieved. The first step is figuring out what people with dementia want from the care system.

# Chapter 4: The Voice of People with Dementia

## Introduction

This chapter considers what people with dementia want from health and social care provision, irrespective of where that care is provided. The debate about the continuum can sometimes be dictated by concerns about care structures, care process and the cost of care, without much consideration of what people with dementia say is important to them. The vast majority of people want to remain in their own homes as surveys time and time again have revealed. What is more important is how people with dementia are valued within the care relationship, irrespective of where care is provided. Being valued incorporates all of the human attributes that people view as important with or without dementia: to maintain self; to be respected; to have autonomy; to have dignity; to belong; to have meaning, to be connected; and to have security. So before we explore the options along the continuum, it is worthwhile reminding ourselves what people with dementia say is important to them, particularly in relation to care provision and care arrangements. How care is understood and delivered to people with dementia matters just as much as where care is delivered.

The WHO (2017 p.5) state dementia care should be ‘sensitive to the needs, expectations and human rights of people with dementia’. People with dementia need integrated, person-centred, accessible, affordable health and social care, including long-term care, to maintain a level of functional ability consistent with their basic rights, fundamental freedoms and human dignity (WHO, 2017 p.23). Prince et al. (2013) agree, characterising quality care as ‘the maintenance of personhood and wellbeing through a conducive physical and social care environment’. Care should be comprehensive in the sense of supporting the person with dementia across their care journey. Van der Roest et al. (2007) argue that healthcare systems should be reformed from service-based to ‘demand-directed care’ and ‘experience-orientated care’ i.e. care that is aligned to the individual experience and needs of the person with dementia (and their carers). An important first step, therefore, is to ascertain the preferences and expressed needs of people with dementia. In short, what do they want? This chapter explores the subjective (i.e. expressed by the person him/herself) lived experiences and needs of people with dementia.

## Qualitative Evidence Synthesis

A number of reviews have synthesised the qualitative evidence on the lived experience of people with dementia. We examine these reviews for the purpose of eliciting the expressed preferences of people with dementia in relation to care requirements, wherever that care is provided. Although not always focused specifically on what people with dementia want in relation to health and social care provision, these reviews provide helpful pointers as to the approach to care that people with dementia find supportive at any stage of the continuum.

*People with dementia living at home*, von Kutzleben et al. (2012) conducted a systematic review of reviews exploring the expressed subjective needs and demands of people with dementia living at home. Six reviews were included cumulatively representing at least 220 studies, including qualitative, quantitative and mixed method studies. People with dementia expressed a wide range of emotional and psychosocial needs across these studies. Their main needs were identified as: (1) to maintain their personhood, (2) to be taken seriously and understood, (3) to maintain normality and hold on to their former identity, (4) to be useful to others, make plans for life, and maintain a healthy lifestyle, (5) to continue their relationships and to live with their partners in their own home, (6) to come to terms with dementia and adjust to a changing life, and (7) to be personally included in the diagnostic and treatment process.

These needs provide direction as to how healthcare providers/systems can best support the person with dementia in relation to healthcare provision: (1) to have access to suitable individual care at all stages of the disease, (2) to be continuously informed and supported during the course of the disease, (3) to be understood and treated as adult and accountable persons by professionals, and (4) for communication to be of “good quality”. Personalised care is seen as a key element of the care process, alongside information and respect. People with dementia defined communication as poor if they perceive professionals lack interest in their subjective needs and demands, do not take them seriously, or provide ambivalent or no information around their diagnosis (von Kutzleben *et al.*, 2012).

De Boer *et al.*'s (2007) review of the literature focused on the experience of living with dementia. All included papers (n=50) recounted direct quotations, to capture the experience ‘*as told by*’ people with dementia. Two key themes were identified as reflecting people with dementia’s experience and response to living with dementia: impact (losses/changes, relationships, care and assessment, and feelings) and coping (denial/avoidance, minimisation and/or normalisation, continue living and fighting back, compensating, and coming to terms with the disease).

This review also describes the activities that people engaged in to ‘*fight back*’ or ‘*compensate*’ in order to continue to live their lives in the best possible way. These reflect the actions that people with dementia take to add quality to life and consequently are potential areas healthcare professionals could target as interventions. Actions taken by the person with dementia included: sticking to daily routines and staying engaged in activities to retain control over their lives, managing symptoms e.g. taking medications, making use of memory aids such as lists, using strategies to keep communication going, and focusing on what they can as opposed to what they cannot do.

Maximising their sense of autonomy is a key outcome for people with dementia (Bamford & Bruce, 2000; de Boer *et al.*, 2007). A key message for healthcare workers is the importance of keeping a focus on the person’s abilities and skills. People with dementia want information about dementia, but they also want to be involved in decision-making about their own care. Unfortunately, there is evidence that people with dementia are not always included in shared decision-making (Miller *et al.*, 2016; Taghizadeh Larsson and Osterholm, 2014; WHO, 2017). People with dementia talk about being ‘*unheard*’ and not ‘*listened to sufficiently*’ (Tyrrell *et al.*, 2006), underlining the importance of involving people with dementia in decisions around their care. This is very important in regard to placement decision-making. People with dementia want to live in their own homes within their own communities. Any decision to move people with dementia out of their own homes into alternative accommodation should directly involve the people most affected by the decision. Otherwise there is a clear diminution of autonomy and personhood. Donnelly *et al.* (2018) highlight the many barriers that must be addressed at a cultural, organisational and professional level in Ireland if people with dementia are to be supported to exercise their right to make decisions about their lives. These barriers, which include an absence of standardised institutional practices for shared decision-making and a lack of awareness of the importance of autonomy among health care decision-makers, hamper the full implementation of national and international policy and legislative directives, which promote supported decision-making.

Steeman *et al.* (2006) conducted a meta-synthesis of qualitative studies (n= 33) to better understand the experience of living with early stage dementia. The findings were grouped into pre-diagnostic, diagnostic and post-diagnostic phases. Transitioning these stages was found to be a very individualised and emotional experience. Similar to the findings already described, people with early-stage dementia were found to experience growing awareness, uncertainty, and struggled to adjust to the changes to their daily life brought about by the disease. People oscillated between self-protection and self-adjustment. Focusing on healthcare provision, Steeman *et al.* (2006) conclude that how professional caregivers interact with people with dementia and their families can support or hinder their efforts to deal with the changes brought about by dementia. They comment that to provide the best possible care healthcare

professionals should *'listen carefully... help them to understand the disease and its consequences, and look for ways to help them face threats positively'* (p.735). They add that the person should be included in their care as *'active and dignified participants'*, for example through, *'boosting their self-esteem without disguising problems and providing hope, as appropriate'*. Interactions should be positive, supportive and reinforcing for the person with dementia.

Van der Roest *et al.* (2007) explored the subjective needs of people with dementia living in the community with an emphasis on their experiences, what is important for their daily life, and for their quality of life. The subjective needs identified within the domains of quality of life were categorised under: self-esteem/self-image (e.g. need to be accepted, respected and valued), social contact (e.g. need for contact with others was a precondition for people with dementia's well-being, especially contact with family), enjoyment of activities (e.g. need to engage in activities that are enjoyable), being useful/giving meaning to life (e.g. to be useful, have a goal), attachment (e.g. wish to continue to live in their own home, fear of being a burden), self-determination and freedom (e.g. need to be in control, to act and decide), affect (e.g. the need to be understood), physical and mental health (e.g. desire to have good health, expressed need around being active, maintaining health), security and privacy (e.g. fear of being abandoned, to know that they will be cared for), finances (e.g. financial security), spirituality (e.g. need to have God in their lives, observe religious activities), and sense of aesthetics in living environment (e.g. appreciation of being outdoors in nature, music, art). In regard to healthcare provision specifically, van der Roest *et al.* (2007) report that people with dementia want professional/informal care that supports them (and their carers) to live in their own home. Remaining in their own home is a constant theme in the literature and reviews analysed for this report. So too is respect for the autonomy of the person with dementia.

Gorska *et al.* (2018) carried out a meta-synthesis of qualitative studies (n=34) that focused on first-hand experience of living with dementia. The aim was to explore relationships between factors affecting peoples' experience and issues relating to participating and adaptation. Three overarching themes were found: (1) living with change (e.g. changes in cognitive capacity, social connectedness etc. impacted on the person's ability to successfully accomplish their daily activities and to participate in life, in turn changing their sense of self and others' perceptions and attitudes to them) (2) striving for continuity (e.g. amidst these continuous changes the person strives to maintain continuity, their identity, sense of agency, connectedness etc.) and the (3) the double-edged impact of the environment (e.g. interpersonal relationships, physical and sociocultural environment can either enable or disempower the person, access to outdoor spaces was particularly associated with wellbeing, and familiarity of spaces and objects support a sense of coherence). These three factors (themes) and their underlying constructs continuously interact to shape the person with dementia's experience.

The time leading up to diagnosis was particularly difficult for the person with dementia and was associated with fear and uncertainty, suggesting that healthcare professionals should be particularly aware of the person's need for information and reassurance at this stage. Societal perceptions of dementia often fed into this fear, suggesting that informing the public about dementia is also important. Having some control over decisions also impacted positively on quality of life and sense of self, emphasising once again the importance of keeping the person at the centre of decision-making, particularly in relation to choices along the continuum. Similarly, maintaining continuity and normality (e.g. continuing roles, routines, and remaining involved in usual activities in their own community) was found to support identity and personhood.

A metasynthesis by O'Rourke *et al.*, (2015) incorporating eleven studies, representing a combined sample of 345 people with mild, moderate, and severe dementia, identified six *'critical concepts'* for enhancing quality of life for people with dementia: (1) connectedness, (2) relationships (together vs. alone), (3) agency in life today (purposeful vs. aimless), (4) wellness perspective (well vs. ill), (5) sense of place (located vs. unsettled), and (6) happiness and sadness.

Four factors (Concepts 2, 3, 4, 5) are described as *'influencing factors'* because in combination they were found to support (or hinder) feelings of connectedness. The factor *'happiness and sadness'* (Concept 6) contributes to either good or poor quality of life. *'Sense of place'* describes the bond the person feels with their immediate environment. Feeling at home or rooted enhanced quality of life; a sense of displacement negatively impacted on the person's quality of life.

Interestingly, Wolverson *et al.*, (2016) aimed to synthesise people's positive experiences of dementia to understand what it means to "live well" with dementia. The synthesis included 27 qualitative studies, representing 439 people with dementia. The analysis sought to identify and extract positive experiences/states and their related themes. Three superordinate themes were identified: engaging with life in ageing; engaging with dementia; and identity and growth. Engaging with life in ageing indicates that people with dementia work to actively engage with and appreciate life (as opposed to live with dementia). There was a strong sense of agency among people with dementia i.e. they actively sought to engage in meaningful and pleasurable activities. Three subthemes were identified: seeking pleasure and enjoyment; keeping going; and love and support. The strong agency of people with dementia is evident in the subtheme *'keeping going'* which reflects the energy, persistence and purpose it takes to keep going.

The importance of preserving identity was a major concern for people with dementia. Wolverson *et al.* (2016) note that a person centred approach to dementia is essentially about maximising the potential of the person. Therefore, valuing the capabilities, strengths and resources of people with dementia is central to providing truly person-centred care. They contrast their finding of a *'preserved sense of agency'* to a *'loss-deficit'* paradigm, arguing that a focus on the positive might provide a... *'first step towards understanding the conceptual domains that might underpin positive adjustment in people living with dementia'*. Their concluding statement makes an important point *'a positive person-centred approach to dementia care and research should transcend any ongoing debate about whether or not such experiences can be regarded as real and instead should look toward how they can be facilitated and maximised in order to help the individual living with dementia achieve his or her optimal level of functioning'*. The review supports the findings of others that good dementia care is person-centred and responds to the individual needs and preferences of the person. The added value of the review is the finding that people with dementia have strong agency and are active in shaping their world. This point is underestimated by healthcare professionals when planning and delivering care.

Residential Care, Cadieux *et al.* (2013), in contrast to the other reviews, focused on the needs of people with dementia living in long-term care. A total of 68 studies were included in the review, the majority of which used a quantitative design (n=50). Unlike the other reviews reported here, Cadieux *et al.* (2013) have not included studies that reflect solely the perspectives of people with dementia but any study that described the care needs of people with dementia living in long-term care. Analysis of needs identified 19 categories: management of behaviour problems, need for daily individualised activities/care, social needs, emotional needs/personhood, ADLs, need for independence, cognitive needs, need to be safe/secure, general overall physical health, need to be in a homelike comforting environment, need to receive proper pain management, sensory needs, need for daily structured care, functional needs IADLs, need for knowledgeable staff, sexual needs, need for privacy, money-financial issues, and spiritual needs. These needs are listed in order of highest to lowest number of times mentioned in studies. The qualitative studies included in this review were found to prioritise emotional needs, personhood, social needs, and individualised activities/care. This review was the only one found to focus specifically on the needs of people with more advanced dementia, suggesting a gap in the literature. The findings overlap with those of other studies reported here but do not explicitly reflect the expressed needs of people with advanced dementia themselves. However, the fact that emotional, social and personhood needs emerge as most important is significant.

## Common Themes

Living with dementia is a highly individualised and emotional experience. However, the analysis of various reviews for this report reveals common themes across individuals' experiences. These can be grouped into two broad categories: maintaining personhood and identity; and leading purposeful and meaningful lives. Steeman *et al.*, (2007, 2013) add an important dimension to understanding how healthcare professionals/services can help people with dementia maintain their personhood and identity by promoting a sense of being valued. Over time a shift in what '*being valued*' meant occurred, from '*being valued for what you do*' (e.g. being in control, autonomous, independent, and fulfilling perceived societal expectations) to '*being valued for who you are*' (e.g. greater emphasis on personal characteristics such as being wise, being a fighter, and focusing on past achievements). Steeman *et al.*, (2013) argue that identity is maintained by '*accepting loss and shifting values*'. Professional caregivers are well placed to support the person to preserve their identity and personhood through demonstrating their recognition of the person's value, for example, by listening to (and documenting) their life story, maximising their capabilities, planning care that aligns with their interests etc. How professionals interact with people with dementia is fundamental to the latter's quality of life. Put simply, people with dementia want to be treated as "*normal human beings*" (Beattie *et al.*, 2002).

The viewpoints of people at more advanced stages of dementia are poorly represented in the research evidence. To date, research on the subjective needs of people with dementia in the main reflects the needs of people in early to moderate stage dementia. This gap in knowledge is important because people with severe dementia may be more at risk of having to leave their own home to live in alternative accommodation. The findings of Cadieux *et al.* (2013) suggest that those at advanced stages of dementia that require them to live in long-term care are likely to have different needs. Carrying out research on what these challenges are is difficult however, as people with more advanced dementia have greater difficulty communicating their needs. However, people with dementia can articulate their views, needs and concerns even at more advanced stages of dementia. Listening to and, more importantly, acting on their subjective expressed needs is critical, especially responding to the most important question of all - where they want to live?

## Conclusion

The overwhelming evidence is that people want to stay in their own home. However, Prince *et al.* (2013) argue that differentiating which (home or residential care) is the best place to be cared for is sometimes more nuanced than at first appears. Simply put, people make different choices in the context of degree of disability and the choices available (Guo *et al.*, 2015; Prince *et al.*, 2013) with some preferring to be cared for in long-stay care facilities under certain circumstances. However, irrespective of location, a sense of belonging, meaningfulness, security, identity and autonomy, have been found to be critical to generating a sense of home (Cooney, 2012; Forsund *et al.*, 2018). The generation and promotion of '*at homeness*' in the care setting is a major contributory factor to the quality of life of people with dementia. What is important is that people with dementia are provided with the right care (appropriate to their needs and that respects their preferences), in the right way (person centred and integrated), at the right time (in context of the stage of disease), and in the right place (a range of alternatives). Crucial to getting '*it right*' is prioritising the voice of people with dementia. This fact is important to remember as we examine the range of alternative accommodation models for people with dementia in the remainder of the report.

# Chapter 5: The Continuum of Care in Ireland

## Introduction

This chapter is more about what we do not know than what we do know. Most people are familiar with the stylised fact that the best estimate of the number of people with dementia in the country is 55,000. What is less articulated is how little we know about the living arrangements of the dementia population. It is accepted that the majority of people with dementia live at home and the remainder live in residential long-stay care or nursing homes (See Chapter 2), but even within the dichotomy of home versus residential care, nuanced information on diagnosis, severity and satisfaction is scarce. The situation is similar when it comes to information on care settings for people with dementia along the continuum of care, particularly in relation to alternatives to nursing home care. ALONE have produced a very useful report on housing choices for older people in Ireland, but did not specifically address the housing needs of people with dementia. Similarly, although the Department of Health, through its Health Service Capacity Review (Department of Health/PA Consulting Group, 2018), produced forecasts on future home care needs and long-stay bed requirements, it had nothing to say on alternative forms of housing provision for older people, either generally, or specifically for people with dementia. In truth, the continuum of care for people with dementia is poorly developed in Ireland, which explains why it is so rarely mentioned when it comes to future provision. This chapter sets out what is currently known about the current continuum of care for people with dementia in the country.

## Ageing in Place

Ageing-in-place is open to many interpretations and meanings. Place can be a nebulous concept that for most people is linked to the space, real or imagined, that people normally call home. For others, place is a more fluid concept, changing in meaning across the life-cycle as opportunities, circumstances, distances and relationships evolve over time. In relation to the question in hand, ageing in place is often associated with living at home in the community, with some level of independence, rather than in residential care (Davey *et al*, 2004; Davey, 2006.). Ensuring that people stay in their homes and communities for as long as possible also avoids the expensive option of institutional care. Thus, it is often favoured by policy makers, health providers, and by older people themselves (World Health Organization, 2007). Two of the United Nations General Assembly (1991) principles for older people specifically relate to this concept: older persons should be able to live in environments that are safe and adaptable to personal preferences and changing capacities; and older persons should be able to reside at home for as long as possible.

While ageing-in-place is, therefore, a complex process, it has been mostly used in dementia care to support care in the home over care in residential care. The Report on the Review of the Nursing Home Support Scheme (NHSS) recommended that the appropriate government departments and the HSE explore the potential for developing sheltered or supported living arrangements as an alternative to residential care. The 2016 Action Plan for Housing and Homelessness, Rebuilding Ireland, notes that older persons have specific housing requirements such as being in proximity to their family and social networks and having access to public and other essential services, recreation and amenities. It also refers to a new cross-departmental/ inter-agency approach including the development of appropriate pilot projects by Local Authorities (Browne, 2017). The recent joint Policy Statement by the Department of Health and the Department of Housing, Planning and Local Government on housing and older people is an example of this kind of inter-agency co-operation (Department of Housing, Planning and Local Government and the Department of Health, 2019).

## Universal Design

The Disability Act (2005) describe Universal Design as *design and composition of an environment that allows understanding, access and use to all people, regardless of their age, size, ability or disability*. In practice that means designing buildings, living spaces, products, services and ICT that meets the needs of all people across the life cycle. Universal Design seeks continuous improvement in mainstream designs as well as assistive designs that facilitate participation and inclusion in economic and social life. The concept of 'lifetime housing' has been endorsed by the Department of Environment, Heritage and Local Government (2007) in their 'Quality Housing for Sustainable Communities' report which outlines that new housing needs to be accessible for younger people, older people and people with disabilities and that designers need to consider the current, future and changing needs of the prospective occupants.

The Centre for Excellence in Universal Design has outlined key principles for the design of housing for dementia that may facilitate ageing in place and reduce the need for much adaptation as people transition from independence to dependence (Centre for Excellence in Universal Design, 2015):

- integrated into the neighbourhood
- easy to approach, enter and move about in
- easy to understand, use and manage
- flexible, safe, cost effective and adaptable over time.

An expanded set of principles to guide dementia-friendly design emerged from research by Pierce et al (2015) for the Centre for Excellence in Universal Design, including:

- participatory approach to the design process, involving the person living with dementia, their family and other carers
- familiar design with recognisable features that are consistent with users' expectations
- 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
- good visual access to key areas or to important objects to remind and prompt the person with dementia when required
- an environment that is calm, and seeks to reduce noise and visual disturbance
- unobtrusive safety measures to protect from hazards
- a personalised environment that promotes the person's individuality and where they can feel at home
- safe and accessible outdoor spaces which can be seen from the interior to encourage the occupant to use the facilities
- promote independence, autonomy, choice, confidence, meaningful activities and engagement with family and the wider community

These principles have practical implications for housing design for people with dementia (Amarach Research et al, 2016), including: houses not having a hall, rather an American-style entrance leading to a living space; having an open floor plan with large sliding doors; visible bathrooms close to the bedroom; large windows; and space at the front for mobility aids. The open plan nature facilitates safer mobility and allows for smells to waft from the kitchen, which can help trigger appetite and healthy eating. In terms of interior design, features should be familiar to the older person. The walls should not have patterns and prints, which can be mistaken for depth and cause confusion. The walkways should be wheelchair accessible and kept free of clutter. The toilet spaces should be fitted with grab rails. Ambient light can help regulate sleeping patterns and improve quality of life. Thermal comfort is very important for people with dementia and houses should be fitted accordingly.

## Adaptive Housing

One of the key factors in allowing people with dementia to live in their own homes is the quality of their housing. A quarter of people aged 55 and over report having difficulties associated with housing maintenance (Gibney, *et al.*, 2018). Over one-fifth of people from the same survey report having housing facility problems, including shortage of space, homes too big for current needs, lack of indoor flushing toilet, lack of a bath or shower, lack of downstairs toilet/bathroom facilities and lack of place to sit outside. Similarly, Amarach Research *et al* (2016) report that just over one fifth of people aged 70 years and over are negatively affected by type of housing and location, at 21% and 22% respectively. While we do not know how many people reporting difficulties have dementia, it is safe to assume that housing difficulties do affect people with dementia. At a basic level therefore, we need to address the issue of people with dementia living in housing that does not meet their needs as they age and particularly as their mobility decreases. While carrying out adaptations is often seen as a priority for older people returning home from hospital, modifications can also be important in keeping people well in the first place and contributing to a safe and healthy lifestyle. Typical adaptation includes: bathroom aids; hoists; rails; assistive technologies; and non-slip floor surfaces. Clúid Housing has recommended flexible schemes for adaptation and the careful redesign of homes which would allow for multiple uses as the person's needs change over time (Fox and Kenny, 2015).

**Table 5.1: Housing Aid for Older People Scheme: Number of Grants and Value of Grants**

Year	Number of grants paid	Total value of grants paid €'000	Average value per grant paid €
2008	1,439	6,421	4,462
2009	4,294	19,345	4,505
2010	7,205	30,775	4,271
2011	6,510	27,098	4,163
2012	4,848	19,910	4,107
2013	2,815	11,247	3,995
2014	5,648	13,498	2,390
2015	3,127	11,267	3,603
2016	3,425	12,647	3,692
2017	3,558	13,258	3,726
2018	3,640	13,904	3,820

Source: <http://www.housing.gov.ie/housing/statistics/social-and-affordable/other-local-authority-housing-scheme-statistics>

The Housing Aid for Older People scheme provides grants to assist older people living in poor housing conditions to have necessary adaptation, repairs or improvements carried out in their homes. The maximum grant available under the Housing Aid for Older People Scheme is €8,000, which may cover 95% of the approved cost of adaptation works. The grant is funded 80% by the Department of Housing, Planning and Environment, with 20% contribution by the Local Authority. The total grant has been volatile over the past ten years, ranging from €6,421m in 2008 to €30,775m in 2010 (Table 5.1). The total value of the grant was €13,904m in 2018, with an average value per grant of €3,840. There is no data on the number of people with dementia supported by the housing aid grant.

The administration of the Housing Aid scheme has been criticised for the demands it places on applicants (Age Action, 2018). The process also differs depending on where you live; some local authorities are better than others in administering the scheme. There are multiple potential tasks involved in applying for the grant including: engaging with an occupational therapist to specify adaptations; getting support from a general practitioner and possibly a consultant geriatrician; engaging an architect; applying for planning permission if new construction is necessary; having to show proof of payment of property tax or deferral through online system; showing proof of

social welfare payment (involves visiting the office or sending a letter of request); dealing with the builder; and negotiating on-going relationships with the Local Authority. The process of applying for housing aid can take up to 18 months to complete from beginning to end. It also requires the older person to have access to significant funds for costs not covered by grants, such as architect's costs and builder's deposit. Age Action (2018) argues that this prevents many older people from applying for the adaptation grant. Moreover, there is a growing over-reliance by older people on the private rented sector, but private rented accommodation is not normally available to tenants for modification, unless by agreement with the landlord.

### **Home Sharing**

Home sharing involves older people opening up their home for co-habitation with other people, mainly younger people with housing needs. The relationship is a reciprocal arrangement - both the homesharer and the householder have something they need and something they can bring to the homeshare relationship. Typically the arrangement involves householders, who are in need of some help and support and have a home that they are willing to share, and younger people, who need somewhere affordable to live and are willing to give some support in return for a room (HomeShare, 2018). The support provided by the homesharer might include help with daily living tasks such as; cleaning, shopping, gardening, overnight security and companionship. The sharer does not provide personal care to the homeowner. Homeshare has advantages for the home owner who gets companionship and low level support and for the homesharer who gets an affordable place to live at a time when accommodation is scarce and rents are high. The sharer is not paying an economic rent, but is expected to contribute to household bills.

The scheme is targeted at older people who are willing to share their home and younger people who need somewhere to live. Brokerage is organised by an intermediary company that links homeowners to potential homesharers. In Ireland, and in the UK this brokerage service is provided by both for-profit organisations and by not-for-profit or social enterprise organisations. After a suitable referral is made to the company, typically from the homeowner themselves or their families, face to face assessment takes place to establish what existing support the homeowner has and whether homesharing has potential in relation to the needs of the homeowner. The homeshare company then identifies potential homesharers who are carefully vetted, including Garda vetting. The sharer is then introduced to the householder and to advocates (family or medical professionals); matching can occur once both parties agree to trade. A homeshare agreement is discussed and finalised with all parties to ensure that each individual's needs and supports are reflected in the arrangement. There is normally a trial period of two weeks before final contracts are signed. Prudent matching of both groups can give the householder the help and security they require and the homesharer the home they seek at a reasonable cost. The cost of the scheme includes a placement fee and an ongoing monthly support fee paid by both parties.

Creating a 'good match' that supports a mutually agreeable sociable living arrangement is a key priority for the broker company. The homeshare arrangement between the two parties is governed by a carefully worded agreement that avoids creating a contract of employment or tenancy rights. While potentially attractive, the scheme is still in its infancy in Ireland. Homeshare does not provide either live-in care or live-in housekeeping, but it does seek to address social need on the part of the home owner and the homesharer. The scheme currently only takes people who are able to pay out-of-pocket for the service, so if it is to develop then it will have to be supported by government in some way, most notably through some type of co-funding model. Referral rates from health and social care professionals are still very weak, with many people unaware of the scheme, while others may be wary of the potential risks associated with safeguarding and security procedures. There is currently no data on whether people with dementia are currently part of homeshare schemes in Ireland. However, there are no reasons why people in the early stages of the disease should be excluded from home sharing arrangements, provided government regulations are in place to support the trade.

## Sheltered Housing

Sheltered housing is primarily a housing model. Occupants have specific tenure rights to occupy self-contained dwellings and in some circumstances they may be able to buy their property. The scheme generally consists of one or two bedroom units as apartments or houses. In recent years Ireland has transitioned from a traditional model of providing housing for older people through local authorities, to a more European-style approach that emphasises the importance of voluntary and non-profit organisations. A good example of the latter is Clúid Housing, a not-for-profit charity and the largest housing agency in Ireland providing more than 5,500 high quality homes. Sheltered housing as defined by Clúid refers to: accommodation for older or disabled people consisting of independent, private self-contained homes which are supported by an on-site Scheme Manager and a 24-hour emergency call system. Some sheltered housing schemes include communal spaces such as lounge/community hall, laundry room and gardens. A warden is usually available, either on site or on a visiting basis.

Sheltered housing has long been promoted as having the potential to bridge the gap between living independently at home and residential care. Thirty years ago, The Years Ahead inter-departmental seminal report envisaged that sheltered housing would form a central part of the continuum of care for older people and recommended that where it is not feasible to maintain a person in his/her own house or in ordinary local authority housing, sheltered housing should be considered as a viable alternative (Working Party on Services for the Elderly, 1988). However, the evolution of sheltered housing has turned out differently, mainly supporting older people who are capable of independent living, rather than needing supported housing with care. As currently operated, sheltered housing is aimed at older people who are at least moderately active and who require little by way of additional support. Access to services and supports is available through generic HSE services provided by local providers. The range of services available to tenants corresponds with the independent living ethos adapted by the majority of the schemes (Irish Council for Social Housing, 2005). High level care services, which are indicative of tenants with higher needs, are not normally provided within sheltered housing units. Home help and day care are used by some tenants, but medical and nursing care are not typically available on site, mainly because such services are not required by tenants capable of independent living.

Most of the evidence in relation to sheltered housing suggests that people are very satisfied with their homes. There were high levels of satisfaction with sheltered accommodation; 90% were 'completely' or 'somewhat' satisfied with their home (Fox and Kenny, 2015). Many more advantages were endorsed (primarily independent living and safety and security) than disadvantages (primarily expensive service charges and not being allowed a pet). In general, residents of these schemes report a good quality-of-life and most enjoyed a good social life. We do not know how many people with dementia live in sheltered housing, but only one housing association in the 2011 Irish Council for Social Housing survey referenced dementia in any capacity, stating that the Alzheimer's Society assist in the running of their day centre and even in that case only one day was specifically designated for people with dementia. People may develop dementia while in sheltered housing, but very few people enter sheltered housing units with dementia. Croucher et al (2006) found evidence to suggest that sheltered housing is often not equipped to meet the needs of people with advanced dementia or others with high needs, and thus cannot provide a 'home-for-life'.

## Supported Housing with Care

Supported housing is a generic term covering a variety of accommodation for older people including: housing with support; extra care housing; dedicated housing with support; and independent housing with support. Occupants usually have specific tenure rights to live in self-contained dwellings, as well as access to significant levels of off-site and/or on-site health and social care, as well as psychosocial support services. Although there is no agreed definition, supported housing can be recognised by several characteristics (Walsh, 2018):

- primarily for older people
- tenure rights are secured
- privacy is guaranteed
- purpose-built, accessible building design that promotes independent living
- safety and security built into design, with fob or person-controlled entry
- fully self-contained properties where occupants have their own front doors
- communal spaces and facilities
- community alarms and assistive technologies
- access to care and support services off-site and/or on site, including emergency care

Supported housing encourages independent living in one's own self-contained dwelling and offers security of tenure. Formal agreements are usually in place to cover the provision of care services and supports, although tenants may not be obliged, as a rule, to obtain their care services from a specific provider. Schemes are intended to support residents with a range of levels of disability, including those with high levels of needs, as well as to provide facilities for members of the local community, in some instances. The scale of supported care models can vary depending on location and the integration of the scheme with local health and social care provision. Many schemes are new-build, although a significant proportion of the smaller schemes internationally have been remodelled from sheltered housing complexes and residential care homes.

In a study of independent and supported housing models in Ireland, the Housing Agency (Molloy and Dillon, 2018) identified nine key criteria associated with existing schemes: ethos; location; design; funding; regeneration; allocations; communal facilities; creating community; and technology. Ethos is focused on achieving the correct balance between respecting a person's privacy and creating a friendly supportive communal care environment. Location emerges as important because schemes that are close to amenities and integrated into the wider community help to promote citizenship and inclusiveness. Sometimes housing schemes for older people can help to regenerate urban and rural areas. Communal facilities help to create and sustain networks and relationships within schemes, while links to the wider community can be fostered through the use of shared facilities whereby community events and older persons outreach programmes are located in the same building. Designing to lifetime home/universal design standards facilitates independence, communication, connectivity and future flexibility. Assistive technology can also help to support the functional needs of people within schemes. Schemes providing higher levels of care supports may require a certain scale to make financial sense, with some suggestion that fifty units is the minimum size for a complex to be able to fund services, especially for people with dementia.

A recent audit by the Housing Agency (Molloy and Dillon, 2018) considered nineteen case studies of independent and supported housing models in Ireland, only two of which specifically referenced people with dementia: Anam Cara in Dublin and the Carebright Community in Bruff, County Limerick. The latter is examined in the next section when we talk about the dementia village experience in Ireland. Anam Cara is a housing with care facility catering for 56 residents in Dublin. The scheme includes people with dementia and other older people with relatively high level of care needs. It is managed by FOLD Ireland and regulated by HIQA, even though the scheme is characterised as a housing model. The accommodation incorporates private living space, shared facilities and communal gardens. Residents have a key to their living space and make final decisions on furnishing within that space. While Anam Cara does not contain independent or 'own door' units, and typically 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 (Pierce *et al*, 2015). It includes a continuous circulation route and the concept of a 'bus stop' as a place to stop and rest, providing 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. The scheme is connected to the community through the church, men's sheds and the local pubs. Families can visit their relatives as they please and there are no restrictions on frequency or timing.

The Housing Agency (Molloy and Dillon, 2018) identified three important lessons from their appraisal of the Anam Cara housing with care model:

- good relationships and pathways of care between general practitioners/primary care/social care and housing providers
- appropriate and integrated funding model for this type of care
- appropriate regulatory standards for this type of housing model.

### **Dementia Village**

Dementia villages are now springing up across the world, with many countries experimenting with this new form of accommodation for people with dementia. There is no uniform approach to the dementia village, but most are self-contained complexes or campuses that help to sustain independent living for people with dementia. In truth, the use of the term village may be misleading, certainly in the Irish context. Typically there is one entrance to the complex that offers connection and protection from the outside world. Once inside, people with dementia live in their own private accommodation, mostly sharing with 4/5 others in specially constructed bungalows or cottages that contain private living space and shared communal kitchens and recreational space. People are free to move around the village space and engage in normal activities like walking, cafe socialising, shopping, art classes, exercise, music and gardening. The guiding principles are familiarity, comfort and like-mindedness. While residents cannot leave the village complex, staff try to create a normal atmosphere by bringing the outside world in through engagement in activities and rituals that happen in all other villages. At the same time, care and support facilities are available from trained staff to meet the health and social care needs of dementia villagers, which for some people may be significant. In many countries, dementia villages are seen as potential alternative to standard residential care for people with dementia.

There is only one dementia village type in Ireland in Bruff, County Limerick. The dementia village which is run by Carebright Community is set on a four acre site in the town beside the local GAA pitch. It is made up of three bungalows, each containing six private accommodation units containing a large bedroom, sitting area, en-suite bathroom and storage. Each resident has their own private external patio directly connected to their living/bedroom space. Each bungalow has a house parent, large communal sitting room, kitchen and dining room. There is a large garden, walking pathways, seated areas and sensory and remembrance gardens. People are free to move around the complex. The village is connected to the outside world through a community hub comprising a community café open to the public, hair salon, fitness centre and large community room and office space, when all are fully operational.

The Carebright dementia village is an effort to recalibrate care and supports towards a more social model of production. People with dementia are encouraged to live independently as far as possible. Each household has decision-making autonomy where residents can get up when they want, go to bed when they want, eat when they want and decide how they will spend their day. People take part in normal daily activities e.g. household chores, gardening, light exercise and social activities such as coffee mornings, singing, art and yoga. Residents and carers organise the weekly shop and cook together. Household life, according to the general manager of the village, is 'normal, spontaneous and full of new experiences'. Dementia design was central to the planning of the bungalows and the external communal spaces. There was a lot of attention paid to natural lighting, sun-downing lighting and automatic lighting in the bathrooms.

It took eight years from concept to the eventual opening of the Carebright facility in Bruff. The capital costs of the village amounted to €5m generated through public, private and philanthropic sources. People with dementia coming into the village are typically early-to mid-stage of the disease and must be able to live and communicate within a group of six people. Residents are funded through the Fair Deal scheme and the 'village' is regulated through standard HIQA procedures. One of the challenges of any new accommodation model is to agree adequate revenue funding with government funding agencies. It is not at all certain that current financial arrangements mediated through the Nursing Home Support Scheme can deliver an integrated social and clinical model of care that promotes autonomy and personhood among residents. There is more work to be done on developing a funding model that can support genuinely holistic models of care for people with dementia.

Some of the key learnings from the Bruff dementia village model, as set out by the Housing Agency (Molloy and Dillon, 2018) and through personal communication from the general manager include:

- the difficulty in finding the appropriate balance between clinical and social care
- the time it takes to change the medical mind-set of clinicians, providers, families and even people with dementia themselves
- the need to make people less risk averse in regard to care provision for people with dementia
- the importance of sourcing the right staff to deliver a more social model of care
- encouraging local GPs and clinicians to engage with residents and visit the village
- the absence of a specific funding model and regulatory scheme that is specific to a more holistic dementia village setting.

### **Small-Scale Residential Units**

The best estimate of the number of people with dementia living in residential care units/nursing homes in Ireland is between 15,000 and 20,000 people (O'Shea et al, 2017). The majority of these residents are living in generic care facilities for older people, most of which are not small-scale or purpose-built for dementia, especially the older capital stock. We do not have good information on where and how people with advanced dementia are being looked after in residential care settings/nursing homes and where, as they approach end of life, they live out their final days. The inner workings of nursing homes in Ireland is very much a black box when it comes to dementia care, even down to reliable estimates of the number of residents with dementia and their levels of severity.

There have been important improvements in the built residential environment in recent years with the adoption of universal design principles leading to better quality of care. People with dementia are particularly sensitive to their environment and good design is now widely regarded as critical to the care of people with dementia. However, while the physical environment is incorporated in legislation and national standards in Ireland (Alzheimer Europe, 2017), there are environmental aspects that still leave much to be desired, especially in relation to appropriate scale and location. Therefore, there is plenty to be done to make nursing homes better places to live, including making sure that future builds are smaller and more integrated into local communities, so that people living in these facilities can live independently for as long as possible and remain socially connected within their own familiar surroundings. This is a real challenge for both the public sector and private providers, but it is a challenge that must be overcome if real change is to be effected. One of the key areas of concern in this regard is the development of a more appropriate funding structure that takes into account the unique and individualised needs of persons with dementia in long-stay settings.

In recognition of the special needs of some people with dementia in residential care settings, the trend in some countries is towards providing specialist care in creatively designed small-scale units (O'Shea *et al*, 2017). Sometimes it may be appropriate to consider a more specialised environment within nursing homes, such as specialised care units (SCUs), for people with dementia, with higher staffing levels, including care from people with an advanced level of dementia knowledge. Very few people with dementia in Ireland (about 11%) have access to SCUs and even when they do, the size of these units does not always conform with best practice models (Cahill *et al*, 2015). Small-scale domestic-type living within SCUs in long-stay facilities in Ireland is rare, in keeping with the general trend in long-stay care settings in the country. While international best practice suggests configurations of no more than 10 people (HIQA, 2009), SCUs in Ireland generally have more than this number, ranging from an average of 29 residents in the voluntary sector, 20 in the private sector and 16 in the public system. Moreover, there is no standard definition of what constitutes an SCU in Ireland or what type of person should be living there, for example should a clinical diagnosis of dementia be always necessary to be admitted to this form of care? Equally, it should be said, there is no agreed definition for the term 'dementia specific bed' within a generic nursing home facility. This all points to a high level of ambiguity within the residential care and nursing home sectors in relation to best practice and optimal care arrangements for people with dementia with different levels of need.

### **Conclusion**

The continuum of care for people with dementia is only slowly evolving in Ireland. Dementia-specific information on that evolution is scarce. What is emerging is the importance of universal design and home adaptation in keeping people living in their own homes for longer, even those with high level of needs. There are a small number of housing with care developments for people with dementia beginning to come on stream, offering potential learnings and pointers for future investment in this area. Part of the learning will surely be the need to improve the level of co-operation between the HSE and the Local Authorities and between the Departments of Health and Housing. It should be housing with care, not housing or care, highlighting the need for joint funding and joint provision. There is only one example of a dementia village in the country, but that too can provide important information on the potential of this type of accommodation to take root, including the budgetary implications in relation to design and care supports. There are signs of small-scale, homelike units emerging in the public long-stay sector and in private nursing homes, but not at a fast enough rate and not in any coherent manner. There is no evidence of any integration between supported housing care and long-stay care provision in the country.

# Chapter 6: Care Setting Preferences

## Introduction

The majority of citizens, irrespective of age, when they are asked about where they want to live say that they want to live in their own homes. There is nothing surprising about this revelation - it is a universal response across all countries. People tend to like where they live and want to remain there in the company of family and friends, living in familiar surroundings and connected to people and places that matter. What is more interesting is how people respond when they are asked to consider hypothetical care setting arrangements in older age, should their functional abilities deteriorate. That question is usually framed in generic terms in relation to not being able to continue to live independently and requiring high levels of care and support as they get older. While it is rare that people are asked in surveys to consider where they might choose to live in the future/later life should they receive a diagnosis of dementia, the independence question usually implies both physical and cognitive decline. While these kind of questions help us to understand people's preferences for alternative accommodation as they get older and potentially more dependent, responses are constrained by people's knowledge of potential care settings and the options available within the country's health and social care system. It is difficult to choose a particular option if you do not know of its existence, and, equally hard to make choices that you know are not available in your locality, region or country. This chapter explores Irish people's attitude to the continuum of care, drawing on a small number of published studies and surveys covering people with dementia, family carers, stakeholders and citizens. Most of the published surveys are focused on issues of relevance to older people generally, especially those attempting to elicit preferences for alternative forms of accommodation, and, therefore, may not always get to the heart of dementia issues. However, the analysis begins with research carried out by Pierce et al (2015) for the Centre for Excellence and Universal Design which does explicitly focus on dementia, specifically dementia and home design.

## Dementia and Home Design

In their work on universal design for dementia, Pierce et al (2015) interviewed 38 individuals from a range of stakeholder organisations including: representative organisations of people living with dementia; government departments; local authorities; housing providers; the HSE; allied health professionals; architects; landscape architects and house builders. People living with dementia, family carers and other family members were also interviewed. We summarise some of the key findings from these interviews below.

There was much variation among stakeholders regarding their understanding and awareness of dementia. 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 the best 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 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. Stakeholders representing local authorities and housing associations acknowledged that some tenants are likely to already have, or would develop dementia in the future. However, they agreed that not enough consideration had been given to dementia specific needs in the planning and designing of local authority housing schemes for older people.

When stakeholders in the study talked about design, they emphasised the importance of accessibility, particularly in relation to hallways, doors, bathrooms, lighting, colour and access to the outdoors. Adaptation and retrofitting existing dwellings to improve design were supported and welcomed by stakeholders, although some warned that change can sometimes be confusing for people with dementia. One carer reported that her husband, who had dementia, responded to an extension to the ground floor of their house to accommodate a downstairs bathroom and bedroom by saying: *I'm lost. I don't know where I am.* Replacing familiar items in the home also sometimes caused problems as described by one family member: *we had taken the range out and put the stove in and he (person with dementia) was like where's the range?* Those with expertise in the area of dementia and those advocating on behalf of people living with dementia emphasised the significance of familiarity in designing or adapting dwellings to make them dementia friendly. There was general support for involving people with dementia directly in the discussion on adaptation and design and for post-adaptation assessment to take place to deal with any problems that might arise.

A small number of people living with dementia and their family caregivers were interviewed to gain insight into key design issues. The biggest issue for one man living at home with dementia was negotiating the stairs to use the bathroom facilities, especially at night: He says: *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.* A woman living with dementia talked about the difficulties she experienced finding her way around her home in which she had lived for all her life: *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.*

The importance of outdoor space was referenced by people with dementia, supported by other stakeholders who noted 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. Others pointed out 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. Outdoor spaces and access to their garden were very important to people living with dementia: *I can show you my spot,* said one man with dementia. *Last Saturday, Sunday whichever day it was, we have a very small garden in the front and 10a.m. out in my sun chair, sorry, my armchair, and I was there until 3 o'clock.* Another woman with dementia said: *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.*

Some family caregivers had thought about the ageing process and their future dwellings needs at an earlier point in the life-cycle. One woman whose husband had recently developed dementia explained that their home was originally built with old age in mind and was now more than adequate for their needs, now that they reached older age: *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's 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.* 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 joint, care-related, 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.*

The potential cost savings arising from improving the dwellings of people living with dementia was also raised by some stakeholders. Good initial design may be cheaper than subsequent retrofitting; it can also keep people living at home for longer. Some people raised questions about the cost of adapting a home and who would bear this cost? As one man put it: *where are people going to get the money to adapt their home?* Some stakeholders referenced how cutbacks in public expenditure have impacted heavily on the availability of adaptation grants, serving to increase the already long waiting lists. People referenced the geographical inequities that exist due to the variations between local authorities in relation to the budgets available to meet local demand. One stakeholder pointed out that there is a huge issue around the house adaptation grant scheme and the availability of funding to do modifications to your home: *Well, it depends on what Council you are in. Some are now experiencing 80 per cent cuts so it depends on what their budget is and the number of people in the area... you get on a waiting list... and... you could actually be on it for four years in some situations.* Some stakeholders reported that only applicants classed as high priority tended to be successful in getting the grant. Very often priority was determined by physical needs, which tended to disadvantage people with dementia, whose main issues related to cognitive decline.

A really important final message from the stakeholders brought together by Pierce et al (2015) was that while buildings, design and the environment were very important, formal care services and supports were even more essential in keeping people living in their own homes. As one stakeholder put it: 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. Family caregivers especially those who had experience of caring for relatives living with severe dementia commented on the difficulties of accessing appropriate services and supports. As one person commented: *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.* There was general agreement that ageing in place can be undermined if formal care is not available to support the unique needs and abilities of people living with dementia and their family caregivers. This is best summarised by one stakeholder who said: *At the moment there are challenges in providing the appropriate quality and quantity of home supports.* This pithy understated comment needs to resonate throughout the discussion on the continuum of care for people with dementia. Without adequate care services and supports for people with dementia, it does not really matter where they live.

### **Choices Along the Continuum**

The vast majority of people want to remain in their own home in older age. That is hardly surprising given that living at home allows people to develop attachments and relationships that help to shape interpretations of the self and notions of identity. Of course, most of us are aware that there may be situations in the future that can lead to home not being possible or practicable due to sickness, physical impairment or cognitive decline. Even then, however, most of us want to stay at home for as long as we can. The focus in this report is on the continuum of care when living at home is no longer possible. The information that is available on preferences for care settings along continuum is scant and fragmented. The surveys that are available are not always focused on the continuum, so sometimes we have to make inference about people's preferences for different care settings from incomplete and uncertain data. The other caveat is that very few of the surveys undertaken asked questions in relation to future potential continuum choices in relation to dementia. The absence of a dementia focus is not likely to make a huge difference to the choices and preferences of respondents in relation to future care settings, but we cannot know that for certain.

**Table 6.1: Preferred Place to Receive Long-Term Care**

Care regime	Very low support %	Low support %	Neutral -neither weak or strong support %	Strong support %	Very strong support %
Care at home	3	4	11	15	67
Supported/sheltered housing schemes	11	16	31	34	9
Nursing Home	30	18	24	19	10

Source: SAGE/Amarach survey: N=1,000

**Table 6.2. Strong or Very Strong support for Supported/Sheltered Housing Schemes by Age Category**

Age Category	Percentage with strong or very strong support for supported/sheltered housing schemes %
16-24	35
25-34	33
35-44	41
45-54	45
55+	56
All age groups	43

Source: SAGE/Amarach survey: N=1,000

The advocacy agency SAGE generated important information on preferences for different types of care settings along the continuum through a national survey carried out by Amarach Research, as reported by Browne (2016). A total of 1,000 citizens were asked about their preferred place to receive generic long-term care should they ever need it in the future. A combination of quota controls and weightings are used to ensure that the final sample was aligned to the population in terms of gender, age, social class and region. Being cared for in their own home is the most preferred option for respondents, should they ever need long term care (Table 6.1). A combined total of 82 per cent of respondents reported either a strong or very strong level of support for care in their own home in the event of ever needing care. People preferred supported/sheltered housing to nursing home care; 43 per cent of respondents exhibited strong or very strong support for supported/sheltered housing, while the corresponding percentage for nursing home care was 29 per cent. Similarly, a significant proportion of respondents (30 per cent) reported very low support for nursing home care; the corresponding figure for supported/sheltered housing schemes was only 11 per cent. For those reporting strong or very strong support for care provided through supported/sheltered housing schemes, the strongest preference is to be found in the 55+ age category at 56 per cent (Table 6.2).

A survey by Amarach Research et al, (2016) on people aged 55 years and over, commissioned by the Housing Agency and ISAX, found, once again, that older people preferred to live in their current home in later life (Table 6.3). Current home was mentioned by 90 per cent of respondents when they were asked about their top three places to live in later life. One third of respondents referenced independent living with care in their top three preferences, while only 9 per cent mentioned nursing homes.

**Table 6.3: Preferred Place to Receive Long-Term Care**

Preference for living in later life	% mentioning in top three preferences
Current home	90
Smaller place in current neighbourhood	21
Retirement community	16
Independent living with care	33
Nursing home	9

Source: Amarach Research et al (2016): (N=554)

This predilection for home is confirmed for the same sample in their response to a question on whether they had ever considered, or were currently considering, particular accommodation options in later life. The vast majority of people had not considered, or were not currently considering, moving from their present home (Table 6.4). That included no consideration of: selling up and buying a smaller property; moving closer to care facilities; moving to a retirement village; moving into independent living with care housing; or moving into a nursing home.

**Table 6.4. Considering Accommodation Options for Later Life: People aged 55+**

Option	Have not done and not considering %	Have done %	Thinking about/looking at/actively considering %
Sold/selling my property and buying something smaller	88	5	8
Moving closer to care facilities once I reach a certain age	93	1	6
Moved/moving into retirement village	95	1	5
Moved/moving into independent living with care facilities	94	1	5
Moved/moving into a nursing home	95	0	5

Source: Amarach Research et al (2016): (N=554)

People aged 55 years and over were very positive about adapting their own house in later life, with 87 per cent reporting positive feelings (Table 6.5). Just under one third of respondents had positive feelings towards moving into independent living with care facilities, while more than half responded negatively to that option. The majority of respondents (71 per cent) had negative feelings towards moving into a nursing home, with only 12 per cent reporting positive feelings.

**6.5. Feelings Around Possible Future Options for Accommodation: People aged 55+**

Option	Positive Feeling %	Negative Feeling %	Neutral %	Don't know
Adapting own house	87	5	6	2
Moving in with own children	22	53	16	9
Moving into independent living with care	31	51	15	3
Moving into nursing home	12	71	15	2

Source: Amarach Research et al (2016): (N=554)

### Older People's Views on Independent Living with Care Facilities

The Housing Agency and ISAX commissioned survey (Amarach Research *et al*, 2016) delved deeper into people's understanding of, and interest in, moving to independent living with care facilities. When respondents were asked about the factors that might encourage them to move to independent living with care facilities, depleting physical health was the primary driver of any potential move (Table 6.6); just under half of respondents (46 per cent) cited health reasons as encouraging them to move. Access to supports and services was cited by 30 per cent, followed by safety and security by 29 per cent. The top two factors that might prevent a move to an independent living with care facility (Table 6.7) were loss of independence (40 per cent) and an unwillingness to sell/lose their own home (39 per cent). More than one quarter of respondents cited concerns about being cut off from family and community as reasons for not moving to housing with care.

**Table 6.6 : Top 5 Factors Driving Potential Move to Independent Living with Care: People aged 55+**

Factors driving potential move	%
Depleting physical health	46
Having access to supports and services	30
Feeling safer and more secure	29
To remain independent for longer	28
Depleting mental health	25

Source: Amarach Research *et al* (2016): (N=554)

**Table 6.7: Top 5 Factors Preventing Potential Move to Independent Living with Care: People aged 55+**

Factors preventing potential move	%
Would feel less independent	40
Unwilling to sell/lose home	39
Would feel cut off from community	28
Would feel cut off from family	26
Don't want to live with other older adults	25

Source: Amarach Research *et al* (2016): (N=554)

The survey also asked older people about the type of features and amenities that would make independent living with care facilities attractive in the event that there was no choice but to move there (Table 6.8). The most important feature for respondents was having their own independent house/apartment (80 per cent). People also wanted safety and security staff on site, as well as having nursing support and treatment rooms for healthcare staff. Two thirds of respondents valued having an outdoor garden/outdoor space on site. Older people valued a combination of facility-specific features and wider amenities, such as public transport, banks/post office and shops, when asked about the ideal mix of features in independent living accommodation.

**Table 6.8. Top 10 Features in Independent Living with Care Facilities: People aged 55+**

Features	% desiring these features
Having own independent housing/apartment	80
Safety and security staff	78
Nearby shops	74
Nurse on site	72
Lift	68
Public transport (bus stop/train station)	67
Own garden/outdoor spaces	66
Treatment rooms for health care staff	66
Nearby bank/post office	65
Spare bedroom	63

Source: Amarach Research et al (2016): (N=554)

### Citizens' Assembly on Ageing

The Citizens' Assembly spent two weekends in June and July 2017 considering how to best respond to the challenges and opportunities of an ageing population. Over two weekends the members of the Assembly heard from 15 experts and 3 individuals who shared their personal experience of ageing in Ireland. They actively took part in over 25 hours of listening, discussion and deliberation. In addition, the Members prepared diligently for meetings, reading papers in advance and reviewing the submissions received by the Assembly on this topic. The Assembly's recommendations were determined by a balloted vote, details of which are available on the website [www.citizensassembly.ie](http://www.citizensassembly.ie).

**Table 6.9: Where Do You Believe Any Additional Funding for Older People Should Primarily Be Spent?**

Continuum Option	Weighted score	Overall rank order
Home care services and supports	189	1
Community-based integrated housing models	168	2
Residential care services	104	3

Source: Amarach Research et al (2016): (N=554)

Only one of 21 votes taken at the Citizens' Assembly on Ageing is relevant to this report, but it provides an important insight into the thinking of citizens in regard to the continuum. Members were asked to vote on the following question: *where do you believe additional funding for the care of older people should primarily be spent?* While not specific to dementia care, members were given three options; home care; supported housing; and residential care - see Figure 6.9 for precise wording of the question. The option ranked 1 received a weighting of 3, the option ranked 2 received a weighting of 2 and the option ranked 3 received a weighting of 1. It is clear from the weighted responses that members showed the highest level of support for home care services and supports. It is equally clear that citizens strongly preferred spending on community-based integrated housing models over residential care expenditure. It should also be noted that, in a separate vote, the vast majority of the Assembly (91 per cent) agreed that supported housing for older people should be subject to government regulation, similar to the way that private nursing homes are currently regulated.

The Assembly also received submissions from interested parties which are summarised on the Assembly website. Of interest to this report is a submission from one advocacy group, highlighting the importance of the housing adaptation grant in keeping people living in their own

homes for longer. The submission goes on to say that the adaptation grant, as it currently operates, falls well short of expectations, primarily due to weak administration and limited funding. Another submission from an independent contributor calls for greater choice for older people, including retirement communities and supported accommodation, incorporating space for visitors to stay or a live in carer if necessary and access to transport, shopping and leisure facilities. The contributor goes on to say that builders need encouragement to provide housing designed to meet the needs of older persons for 20-30 years, arguing that this would encourage forward planning, downsizing and independent living rather than high cost institutional care with its many drawbacks.

### **Department of Health Public Consultation on Home Care**

Another potential source of information on attitudes to the continuum of care are the submissions to the Department of Health's current consultation process on home care services in Ireland. We have examined the consultation report produced by the Institute of Public Health (2018) for direct references to the continuum, especially the role of supported housing. There were limited submissions on the relationship between home care services and housing options for older people, especially for people with dementia, which would enable the latter to live independently for longer in a range of community-based settings. However, some submissions argued that better use could be made of reablement and housing adaptations to allow older people to stay in their homes for longer. The importance of universal housing and assistive technology was also highlighted in a small number of submissions. There was agreement that supported housing is not well developed in Ireland and that greater investment in home adaptations and more formal housing-with-care models should form part of the new home care legislation. It was suggested that the lack of supported accommodation has resulted in more older people using residential care facilities or staying in hospital longer than necessary, reinforcing the need for a well-integrated supported housing supply with significant home care services and supports attached. The need for a comprehensive policy framework was identified, where care could be integrated with disability, older people, carers, housing and transport policies, all of which were considered essential for wraparound support for people living in the community.

### **Conclusion**

This chapter collated disjointed data on the preferences of citizens and people with dementia for alternative care settings along the continuum of care in Ireland. The information was generated through secondary analysis of a relatively small number of datasets, the majority of which were not dementia-specific. In fact, only one dataset was dementia-specific and it focused on design issues for dementia. People with dementia identified universal design as being very important in both home settings and in residential care/nursing homes. Specifically, people with dementia referenced accessibility, signage, visibility, colour, lighting and outdoor spaces as being important for good quality design. Home adaptation was also valued in later life, as people sought to come to terms with declining physical abilities and complex care requirements through appropriate modifications to the built environment. However, when people spoke about adaptation, they often did so in frustration, mainly due to the cumbersome and restrictive nature of the current public schemes.

Not surprisingly, citizens valued living at home above any other alternative. Supported housing did feature in people's thinking about future needs, but only for a minority. Depleting physical health was the main reason given as to why people might move to housing with care in the future. Even fewer people referenced nursing homes as somewhere they would like to live in later life. The most desired attribute in independent living with care facilities was having an independent house/apartment. Participants in the Citizens' Assembly on Ageing voted for increased public spending on home care services and supports above any other alternative along the continuum of care. Citizens also strongly preferred investment in community-based integrated housing models over residential care expenditure. There was very little explicit

reference to dementia and housing in the recent submissions made to the Department of Health's public consultation process on home care in Ireland. There was, however, an acknowledgement that supported housing is not well developed and that further investment is necessary, especially in relation to home adaptations and different types of integrated housing-with-care models.

# Chapter 7: Lessons from Abroad: Models, Costs and Outcomes

## Introduction

Internationally, the emphasis is on personalised care at home for people with dementia and the increasing separation of social care and medical care at all parts of the continuum. More than two thirds of OECD countries have introduced some form of user-directed support to give more choice and flexibility to people with dementia in relation to the services and supports that they receive (OECD, 2015). Design for dementia has become more important and dementia advocacy groups in a number of countries have produced guidelines for people with dementia and family carers to create a dementia friendly environment at home. A number of European countries are now promoting dementia inclusive communities, including Ireland. Japan is the world leader in this area, incorporating the training of ‘dementia supporters’ (currently over 5 million people) within communities, who wear an orange bracelet to identify themselves and act as advocates within local areas (OECD, 2015). Financial support for home adaptations are provided for people with dementia in some countries. For example, people with a diagnosis of dementia in France, can have their homes assessed to see if adaptation could be beneficial (Alzheimer Europe, 2019). Home adaptation is also part of the public response to dementia in Sweden (Henning, 2009).

The ‘traditional’ model of residential care still exists in Europe and beyond, which is not surprising given how deeply embedded it is in the minds of health care professionals and the general public. However, it is gradually being replaced by a more holistic approach to supporting older people and staff by creating domestic style spaces within more nurturing and mutually supportive environments. Creating genuine caring communities (as opposed to merely providing care) has been identified as a way of shifting from traditional long-stay care settings to locations where people (staff and residents) are engaged in mutually supporting each other. Countries are now looking at living arrangements that combine the best features of traditional residential care (safety, security and access to medical care) with the best features of living at home (independence, familiarity, community and connections). Small-scale (domestic scale) living has been a feature of residential care in some European countries for some time now. Greater independence for residents and the opportunity for residents and families to be more involved in decision-making are key elements of the new approach. So too is creating opportunities for residents to engage in normal everyday activities that reflect their preferences, previous routines and lifelong engagement.

This chapter reports on international developments along the continuum of care for people with dementia, drawing on examples from different countries. The choice of examples reflects general trends along the continuum of care, but they do not and cannot fully cover all that is going on in dementia care across the world. They are snapshots of interesting approaches that Ireland can draw on for inspiration and instruction in regard to potential new directions in this country. The second half of the chapter reports on the evidence in regard to the effectiveness and cost effectiveness of these models. That research is limited and there has been no major trials that we can draw on to compare the cost and benefits of alternative care settings for people with dementia. The reality is that the continuum is only developing and that most countries are in the early implementation and replication stage of new models, rather than having well-established embedded structures. That is not to say that nothing can be learned, or that we have to wait indefinitely for more evidence before making any decisions on investment along the continuum. Rather, it is just to caution that our existing knowledge is limited.

## Homes not Institutions

Several new care models have been developed to implement a process of cultural change in relation to long-stay care, by adapting the physical, social, and organizational environment for people with dementia (Verbeek *et al.*, 2009). Typically, these new models focus on small-scale, home-like care environments, in which the independence of the resident and the normalisation of daily life are emphasized. This model has been implemented in various countries, through group homes in Japan, the Green House model in the USA, shared housing arrangements in Germany and small-scale living in the Netherlands (Verbeek *et al.*, 2010), all of which will be discussed below. In some countries, government policies encourage the development of small-scale, home-like care environments, making them a substantial element of long-stay care reforms. For example, in the Netherlands, approximately 25 per cent of all institutional dementia care is estimated to be provided through small-scale living facilities.

The Netherlands has also been proactive and innovative in relation to housing with care for people with dementia. Wiekslag Krabbelaan is a model of housing with care provision, designed as an alternative to traditional residential care. The objective is to keep people with dementia connected to home, neighbourhood and community. Residents live in two 8-person households where each has their own private bedroom and bathroom space. Dinner is cooked within the household and shared at a single large dining table, as in a family. Residents have access to gardens and remain visible and connected within the neighbourhood. They can leave the household to go shopping with staff or family. The two households share large multi-purpose areas for creative and cultural activities with staff or family members. Care is provided through the Dutch national long term care insurance scheme. This provides a complete package (nursing care, housing, food and cleaning services) but residents are required to make financial contributions according to income, age and domestic circumstances.

De Hogeweyk village in Weesp, near Amsterdam, is designed for people with dementia who can no longer live independently in their own home, but who do not want to go to a nursing home (be: the Hogeweyk care concept, 2018). Like all care homes in the Netherlands, De Hogeweyk is primarily state-funded with some cost sharing among residents. A national insurance system covers the approximate €6,000 monthly cost for each resident, with the richest people paying up to €2,400 into the scheme. The design and care programme is intended to promote residents' self-esteem, autonomy and independence, within a secure and familiar environment (Anderzhon, 2012). Care services and supports, including clinical care, are available 24 hours a day, seven days a week. There are 27 housing units or households, spread across the complex, divided among four different lifestyles; for example, the 'urban' lifestyle denotes informal, gregarious manners, brightly coloured décor, popular music and beer. Each household is self-contained unit, with a budget for food, medicines and care supplies, its own front door and doorbell, 6/7 private bedrooms and two bathrooms, kitchen and communal dining facilities.

The aim of the village model is to replicate daily life in community of households that is compatible with lifestyle choices, thus making residents as comfortable as possible and enabling them 'to continue to live in the manner to which they were accustomed prior the onset of dementia' (Notter, Spijker, & Stomp, 2004, p.449). The dementia village offers a range of onsite facilities, including a garden, town square, restaurant, bar and a theatre that can be used by the residents and people in the surrounding neighbourhoods. Since the residents cannot leave the complex, staff cultivate a more normal atmosphere by bringing the outside world in to the village. The guiding principles of De Hogeweyk are familiarity, comfort and like-mindedness. Staff do not wear uniforms and the ambience is social rather than medical (Glass, 2014).

De Hogeweyk has inspired the development of dementia villages in many other European countries. For example, the first French dementia village, catering for 120 people with dementia, will open in Dax at the end of 2019. The stated objective of the Dax village is to maintain and enhance the participation of residents in community and social life. The village will look like the traditional medieval 'bastide' - a fortified town common in the local area. There will be no visible barriers to the outside world and the complex will be integrated into the social and cultural life of

the city. The households will be distributed around a central square and the complex will include a supermarket, hairdressers and restaurant to encourage social interaction. A novel element of the French approach is the inclusion of an evaluation component into the model, whereby researchers will examine the costs and benefits of the development, including quality of life outcomes for residents. This is a welcome development, given how little evidence exists on the effectiveness of dementia village relative to more traditional models of residential care.

Denmark has given explicit policy priority to community care over residential care, to promote older persons living in their own homes. Since the law on dwellings for older persons of 1987, no new nursing homes have been constructed in Denmark, and instead a wide range of alternative dwellings have been developed (Schulz, 2010). For example, many old nursing homes have been rebuilt to fit the new concepts of close-care accommodation with the adjoining service areas and a permanent staff to service the people living there. A number of these have been constructed as group developments, consisting of 6-10 independent apartments, surrounding a common-room and often with a common garden.

A basic principle of Denmark's long-term care policy is that the type of accommodation should not dictate the offer of care to older people. All eligible individuals have free choice of care providers. These include senior citizen residences, gated communities, assisted living units and nursing homes. Older people living in close-care accommodation may continue to use their usual family doctor and manage their own household. The residents do not lose their normal citizen rights; their apartment is legally their private home with a right of privacy and staff do not take over the responsibility for the life of the individual resident. Each can decide what to eat and where, and what services s/he wants. Personal daily routines are continued as far as possible.

One German-based model that has gained in popularity since first emerging in 1995 in Berlin is shared housing arrangements (SHAs) (ambulant betreute Wohngemeinschaften), in which a limited number of six to eight people in need of care rent private rooms in ordinary apartment buildings, while sharing a common space, domestic support and access to nursing care (Doetter and Schmid, 2018). The concept aims to provide a small-scale, home-like facility with ample leeway for individual activities and autonomy for dependent older people, especially people with dementia. The number of SHAs in Germany have risen from 143 in 2003 to more than 3,000 in 2018, although still small relative to traditional care settings in the country. Sometimes SHAs are fully autonomous and sometimes they are owned by care providers; care is subsidised through the German long-term care insurance scheme. In general, SHAs provide positive stimulation for people with dementia, encouraging residents to engage in meaningful daily routines and activities such as cooking and cleaning. While formal care services and supports are available to people with dementia living in SHAs, the model also relies heavily on the involvement and support of relatives, friends, and community volunteers. Significant levels of cost sharing are involved, depending on location, the choice of carer provider and range of services and supports provided. This can create difficulties for people on low incomes, particularly in relation to access to this kind of model.

Similarly, in Germany, flat living communities (Wohngemeinschaften für Menschen mit Demenz) have been developed for people with dementia as an alternative to traditional residential care (OECD, 2015). These communities contain up to twelve people with dementia who live independently in an apartment or house, which they can furnish with their own belongings. Care is provided by a consistent set of formal providers who become well known to the residents. This model of care is often subsidised by the long-term care insurance plan, although it is unusual for the full cost of care to be covered by social insurance.

Group homes in Japan are a similar concept (OECD, 2015, 2018). Between five and nine people with dementia live in each home. Residents have their own private room, with enough space for a closet and a television, but share communal bathrooms and living areas. At the centre of each home is a large kitchen area and an open meeting space with couches and

tables where residents can sit, relax or eat. Independence is promoted within the group home and people are encouraged to engage in meal preparation, housework and other meaningful activities that reflect their own interests and competencies. A sense of individuality, ownership and community is fostered within the group home. The approach is reflected in the Japanese expression “sono hitorashisa (individuality)” which has the same meaning as personhood (Nakagawa *et al*, 2017). Typically, there are long waiting lists for group homes in Japan, between two and three years in some cases (Traphagen and Nagasawa, 2008).

The Green House model in the USA offers an alternative to traditional nursing home practices and design in that country (Jenkens *et al*, 2011). The Green House idea is to enhance the independence, dignity and well-being of residents through restructuring in three domains: care provision, staffing and the physical environment. The philosophy is operationalised through small private homes, where intentional communities, self-directed teams of caregivers and good design facilitate normal and flexible daily routines that accord with individuals’ needs and preferences. An important feature of the Green House model is architectural design, which accommodates approximately ten to twelve people, each with their own private bedroom and bathroom with access to a communal sitting room, dining and kitchen. A living room with a fireplace, together with the kitchen and dining room, is the centre of life in the home. Each house has proximity to either a garden or green space through a patio or balcony. The Green House model offers residents autonomy as to when they wake up, what they eat and whether or not they wish to participate in an activity during the day and how they engage in activity when they choose to interact. Certified Nursing Assistants (CNAs) (Shabazims) coordinate care in conjunction with nurses and other health care professionals.

Closer to home, Hemsworth Court in Belfast is a multi-award winning, supported housing facility for people living with dementia who wish to live independently in their own home. Tenants are encouraged and assisted to live as independently as possible in apartments especially designed to allow a partner, or carer, to live with the tenant in their own home. The facility is a partnership between Radius Housing and Belfast Trust, who provide 24 hour support according to each tenants individually assessed needs (Radius Housing, 2019). It offers modern, supported housing with associated communal facilities for people living with dementia who wish to live independently. Hemsworth Court is more than just a building project. It is also about community, social inclusion, wellbeing and quality of life. The Lower Shankill area of Belfast, within which Hemsworth is located, is now dementia inclusive with training provided by the Alzheimer’s Society Dementia Friendly programme to empower local people and businesses to understand and support people with cognitive problems.

### **Costs and Outcomes**

While the development of small-scale living facilities as an alternative to residential care is generally seen as positive, the evidence on the effect of these new living arrangements on health outcomes is neither strong or comprehensive, particularly in relation to people with dementia. An early study by Wimo *et al*. (1991) suggests that ‘Group Living’ in Sweden is cheaper compared to the costs of standard nursing home care. However, this study is based on a small population (two group living facilities housing 24 residents), costs such as hospital days and extra support from social services were not included and residents of both settings were not comparable in terms of overall dependency. Svensson *et al*. (1996) suggests that the average costs per patient might be higher in ‘Group Living’ than in old people’s homes, depending on the physical design of the home and the functional ability of residents. Costs tend to be lower when the number of residents per unit increases and when units are attached to other institutional facilities.

There is no clear evidence on the cost effectiveness of supported housing models for people with dementia. There is no trials data and some of the cross-sectional research that has been done is ambiguous. For example, Wolf-Ostermann *et al* (2012) found no clear health advantages for shared-housing arrangements for people with dementia in Germany compared to special care units in nursing homes. One issue with supported housing models is the level of

services and supports available to residents. The cost of care ultimately depends on the range of services and supports available to residents. Moreover, the effectiveness of supported housing schemes and indeed equity of access can be undermined if resource allocation and insurance cover for the model is inadequate (Doeter and Schmid, 2018). In the United Kingdom, Baumker et al (2011) report that extra care housing may be cost-effective, but their study was based on the economic analysis of statistically matched non-dementia samples who had previously moved into residential care, with physical functioning as the main outcome measure.

Although research on the evaluation of small-scale, homelike facilities in dementia care is better, many of the problems remain the same. The definition of small-scale remains problematic. So too does information on the characteristics of people with dementia in small-scale facilities. Moreover, outcomes have not always been well-defined or well-measured. Most studies exploring the effects of small-scale living facilities for older people with dementia suffer, therefore, from methodological limitations, such as small samples (Saxton *et al*, 1998), cross-sectional analysis (Onishi *et al*, 2006) or differences at baseline between residents in small-scale living and traditional nursing home care or no control group at all (Verbeek *et al*, 2009). There is little understanding of the relationship between costs and outcomes, particularly in terms of the services provided, staff training and education, the dependency of residents and the organization of care provision. Given these limitations, it is not surprising to find that the quality of the evidence at this point on the continuum is also problematic (Verbeek *et al*, 2009, 2010, 2014). The De Hogeweyk dementia village, for example, while reporting client and family satisfaction with care arrangements and a reduction in behavioural problems, has not yet undergone comprehensive economic evaluation looking at the relationship between costs and health outcomes (Hurley, 2012).

What is known is that small-scale group living facilities tend to use far fewer restraints and psychotropic medications, an indication that quality of care may be higher (Verbeek *et al*, 2014). People with dementia living in small-scale facilities may also be more socially engaged and less aggressive than residents in traditional wards (Verbeek *et al*, 2014). Staff also report that being close to people with dementia in a small-scale living space allows them to connect more with residents, thereby encouraging positive stimulation (Lee *et al*, 2016). Family members also report higher satisfaction and lower burden in small-scale group homes compared to traditional facilities (Lum *et al*, 2008, Verbeek *et al*, 2010). Some positive results have also been reported in relation to residents' functional status (te Boekhorst *et al*, 2009). A homelike environment and good design has also been found to positively influence residents' daily activities and social interactions (Marquardt *et al*, 2014), including their dining experience in long-term care facilities (Hung *et al*, 2015). In Australia, Dyer et al (2018) suggests that smaller scale, clustered domestic models of care may better meet the preferences of residents and their families, as well as improving health and quality of life outcomes for older people. Studies of the 'Green House' model of small-scale group living for people with dementia in the United States have indicated that quality of life among residents of Green House communities is higher than that of residents in more traditional nursing homes, and quality of care is as good as or better than in traditional nursing homes (Kane *et al*, 2007).

On the other hand, some evaluations have suggested no differences in the quality of life of residents in small-scale facilities (Verbeek *et al*, 2010; de Rooij *et al*, 2012; OECD, 2018). The results on behaviour are also mixed (Verbeek *et al*, 2014). It is difficult, therefore, to be definitive on the effects of care setting on outcomes when some studies report positive effects in specific domains, while others find no such effects. Neither do we know which aspects of small-scale living contribute to improved outcomes, or how they work together, or whether small-scale means the same thing from one study to the next. Sometimes, the small-scale environment may not even be utilised to its full potential, thereby reducing its overall impact on residents (de Boer, 2018). Much more work is needed, therefore, to extend both theoretical and empirical understandings of how people with dementia interact with their environments, so that these spaces can be designed to support the personhood of residents and carers (Day *et al*, 2000; Woodbridge *et al*, 2018). The longitudinal dimension is also absent in the literature. Sustaining

and growing small-scale living facilities, such as the Green House model, requires a highly skilled team of staff with the ability to frequently and collaboratively solve complex problems in a way that supports reinforcement of the model. This finding leads to questions about the type of human resources, practices and policy supports that organizations need to sustain the necessary culture change in the long-run (Bowers *et al*, 2016).

Finally, Easton *et al* (2017) undertook a systematic review of economic analyses of residential care infrastructure that yielded some interesting results. Fourteen studies containing an economic component were identified. None of the studies identified attempted to systematically link costs and outcomes through cost-benefit analysis, cost-effectiveness analysis, or cost-utility analysis. There was also a wide variation in approaches taken in relation to the measurement and valuation of outcomes associated with differential residential care infrastructures: eight studies utilized various clinical outcomes as proxies for the quality of care provided, while two focused on resident outcomes covering agitation, quality of life, and the quality of care interactions. Most disappointing of all, only two studies included residents living with dementia. The review identified four studies that were concerned with environmental design. Environmental modifications in these studies included homelike environments (e.g. single bedrooms, private bathrooms, decorating, and access to outdoors) and functional modifications (e.g. increasing visual access to bedrooms and activity rooms, extending activity spaces, and building partitions to reduce overstimulation). The evidence suggests that environmental modifications come at an additional cost, but are only weakly associated with better outcomes in the form of reduced agitation and improved social interactions.

## **Conclusion**

Many countries are on a journey towards the provision of different models of care for people with dementia. There are now alternatives and community-based demonstrator projects to residential care ranging from universal design housing to housing adaptation to supported housing to small-scale living facilities located on, or in proximity to, nursing home sites. Countries are developing alternatives to traditional long-term care institutions that expand the notion of care beyond clinical improvement and nursing care, embracing greater autonomy for people living with dementia and more independence in their day to day life. But they are doing so against the backdrop of limited information on the cost effectiveness of these different alternatives. This does not mean that nothing should be done until we have better information on the impact of new models on the well-being and quality of life of residents. People have preferences that are leading them to choose different forms of accommodation to care at home or care in nursing homes. And we know from repeated surveys that citizens prefer independent supported housing options to residential care beds. The issue for government is to support informed choices through incentives and regulation that allow those who might benefit from supported housing and small-scale living facilities to move to their preferred option. What is apparent from our review of international developments is that the model of care at any point on the continuum must promote independence and social interaction for people with dementia to the greatest degree possible. That should be the guiding principle for policy-makers as they seek to expand choice along the continuum.

# Chapter 8: Irish Stakeholder Views on the Continuum

## Introduction

A short survey was circulated to 31 key stakeholders and knowledge holders in the area (see appendix 1 for questionnaire). There were 27 respondents to the survey (a response rate of 87 per cent); eight health service managers/service providers, seven with a lead role in relevant community and voluntary sector organisations, four health professionals and eight others (mainly academics and policy makers). The high response rates are indicative of the engagement of these stakeholders in the issues raised by this report.

## Ageing in Place

Among respondents there was a strong, shared understanding of the concept of ‘ageing in place’ as remaining in your home for your lifetime, with supports and adaptations as required: *“Ageing in place describes the opportunity for older persons to live out their later lives in the place where they feel this belonging, familiarity, comfort and safety - and which in many cases is their existing home and their local community”* (R17). Four characteristics were common across most of the descriptions;

- ageing in a setting of the person’s choosing - generally their home *“in most cases people would choose to live at home if at all possible”* (R21)
- the importance of community, remaining connected and good quality of life i.e. ‘ageing well’ *“remaining in their communities and maintaining relationships with family members, friends and neighbours”* (R09)
- the ability to age in place regardless of changing needs
- the need for appropriate care services and supports that are flexible and adapt to changing needs. This included a supportive and dementia inclusive community and society, as well as the availability of formal care services: *“these supports... enable the older person to overcome challenges and difficulties they encounter, as well as to access the resources that will enable them to remain living at home”* (R04).

There was a strong view among stakeholders that the continuum of care should not involve the person with dementia moving from one setting to another, but that an ageing in place philosophy should prevail. Support and adaptation should develop around the person and respond to their changing needs in the place where they currently live: *“The risk of the ‘continuum of care’ approach - is that we adopt a model where people move from ‘place to place’ to get access to different levels of care in different settings as their needs change. Movement, relocation and displacement can be traumatic - so I suspect that we need to explore more universal and acuity-adaptability models so that the ‘places adapt’ and the number of moves can be minimised - or almost avoided altogether”* (R17).

## Barriers to Ageing in Place

Over 25 different barriers were identified that prevent people with dementia remaining in their own homes for as long as possible. These are grouped under four main headings in order of frequency:

- Environmental barriers: relating to the immediate physical environment such as the quality of the housing stock, unsuitable housing i.e. cannot be adapted, and barriers in the wider external environment such as lack of transport. The absence of a comprehensive adaptation scheme was reference by a number of stakeholders.
- Inadequate quantity and flexibility of publicly funded care: particularly a lack of formal support services such as home supports, assistive technologies and personalised supports.
- Social isolation: specifically, a lack of informal supports where the person is living alone and/or where family or friends are not available or unable to provide support; or where the person no longer drives or has no access to transport; and geographical isolation.
- Safety concerns: concerns about risk and families' aversion to risk.

Functional decline, where the person is unable to manage day to day activities, and declining health, while not necessarily barriers to the person remaining at home, can be precipitating or exacerbating factors affecting the ability to remain at home. There was also a consideration of barriers at a more systemic level such as a lack of societal understanding and accommodation of dementia, and a lack of legislation, funding and systems to support ageing in place. The orientation of health and social care services towards congregated care, the lack of alternatives and the comparative certainty provided by Fair Deal funding versus community services all create an environment which almost has an inbuilt bias against ageing in place and towards out of home, residential, congregated care.

A series of questions examined the issues around a number of care options including; adaptive housing (to support ageing in place), supported living, dementia villages, nursing homes and special care units for people with dementia.

### Housing Adaptations

Housing adaptation such as repairs, improvements and modifications can be an important provision for people with dementia who want to remain in their own homes. The main issue identified by respondents in relation to adaptation was the lack of knowledge about and access to funding for such adaptations. The application process was described as complex and not suited to the needs of the person with dementia. Delays in access to and the lack of occupational therapists (OTs) for appropriate assessments is also an issue. Practical barriers include the fact that some housing is not suitable for adaptation, difficulties in engaging builders and the displacement and disruption that can occur, which can be particularly upsetting for a person with dementia. However, positive aspects/solutions were described and included the usefulness of universal design guidelines, the need for greater awareness of these guidelines and the possibility of incentivising universal design so that it becomes the standard in buildings and the built environment into the future.

There was a strong view that there was insufficient use made of low cost solutions such as signage and dementia friendly interiors as well as the need to "use technology to its maximum potential". The fragmentation of aspects of the housing adaptation function between different agencies was highlighted by some, which can lead to a lack of integration, delays and potential duplication of effort. For example, in any given area several NGOs may be involved in 'care and repair' initiatives; the local authorities are responsible for grant funding adaptations and the OTs who carry out the relevant assessments are located within the health service. One suggestion was to focus budgets, systems and responsibility for delivering outcomes with one agency; *"This could be a CHO working with a panel of builders advised by a design specialist (architect and/or occupational therapist) which could work as part of the wider hospital discharge and transfer of care strategies or a social enterprise could be seed funded to develop necessary scale to become effective in this area"* (R16).

### Supported Living/Housing with Care

There was a strong consensus on the value of supported living or housing with care as an option, with many calls that it should be more widely available. The need for expanded choice and options for people to live within their communities was endorsed by almost all respondents. Supported housing was seen as a positive option, offering *“a level of support that gives confidence to the person, supports them with their own independence while providing assurance to families and others that the person is in a safe place”* (R06). Several responses described important features of such developments:

- *“They should be located within the existing care ecosystem of the person living with dementia, and within the area they are familiar with to enable the maintenance of relationships with family, friends and neighbours, the continuation of activities within the community and to support consistency with healthcare”* (R25) and the need for them to be: *“embedded and interacting with the community, becoming an intrinsic part of the neighbourhood”* (R17);
- The focus of these settings should be on *“wellness”* and *“life enhancement”* not just maintenance, so embedding physical, cognitive and social activities is essential (R25), as is access to appropriate outdoor space (R08);
- The importance of an integrative approach was highlighted, with strong emphasis on the care dimension - people should have access to personalised care, that includes psychosocial elements;
- Good design is essential - using principles of dementia friendly and universal design (e.g. Universal Design Guidelines for Dementia Friendly Dwellings, Grey *et al*, 2015);
- Importance of skilled care and housing staff with appropriate training in dementia;
- The importance of clarifying tenancy issues and how they overlap with care and service provision;
- The potential of co-locating with higher-dependency long term care facilities so that if a person’s care needs increase, they can still remain close to home;
- The use of innovative approaches so that these settings are intergenerational and can act as a resource and support for the wider community.

The timing of the move to supported housing can be crucial, not just to ensuring the success of the move but to avoid another move when needs increase: *“Positively re-locating to a unit at an earlier stage may make for a more successful transition - with increased capacity and time to adapt to new people and surroundings. The issue and choice of timing is interwoven with availability, funding linked to diagnosis, and the desirability/attractiveness of the place to the person with dementia”* (R17).

It was noted that, because there are so few developments in Ireland, housing with care is not very ‘visible’ and therefore is often not considered an option as people have no experience of it and haven’t seen it in action. Providing more public information on housing with care options and generating demonstrator projects were seen as important in creating awareness among the public about the potential of this care setting.

### Dementia Villages

While dementia villages were seen as a potential option for some people with dementia, there were strong reservations expressed about this model. Certain benefits were cited such as safety and the possibility that a controlled environment can be enabling and allow an individual with dementia to live well and safely. However, there were strong concerns expressed, based on the fact that these are ‘artificial places’ which essentially ‘invent a parallel community’. One respondent expressed the view that the development of segregated or gated communities where people are grouped together according to their disabilities *“has the potential to lead to isolation and effective ghettoization of people with dementia”* (R05). Another cautioned that *“this (dementia village) arguably goes against all of the national policy and work of the Dementia*

*Understand Together campaign which aims to de-stigmatise dementia and provide for proper integration within communities” (R20).*

There was a strong preference for housing with care as an option over dementia villages. Respondents also noted that the use of universal design and emerging technology should ensure safe places for people with dementia to live in their own community without the need for a ‘proxy-village’. However, one respondent suggested that this model of provision *“may be appropriate for rural Irish communities - where, as a place-based micro-economy, it may reverse social erosion and contribute to more sustainable village development” (R17).*

### **Nursing Homes and Public Long-Stay Facilities**

Survey participants were asked to consider practice and policy issues in relation to the future care of people with dementia in nursing homes and public long-stay facilities in Ireland. Practice issues focused on the need for much greater involvement of people with dementia in their care, greater flexibility and personalisation and the adoption of an enablement rather than a deficits model of care; *“Use the learning from programmes such as Genio, ASI and DSIDC where personal choice and interpersonal presence is core to the practices of the person in their own place” (R03).* The need to move away from risk averse practice was also noted and described as a *‘big cultural shift’*. The need for a skilled, dementia trained workforce was noted and initiatives needed to retain this workforce which can experience high turnover. Several respondents mentioned the need to implement the capacity legislation with appropriate practices for consent and protections against deprivation of liberty.

Greater use of technology and better access to outdoor space were mentioned as areas for improvement. Accommodation that allows couples to remain living with each other after one of them moves to long term care is described as *‘hugely lacking in the system’* and this *‘causes a lot of hardship and unforeseen consequences’*. It was noted that future design and funding models should address the expectation that couples with different care needs will want to remain together. More responsive models will also be needed to meet the needs of other groups such as immigrant populations, people with intellectual disability and people with other disabilities.

In terms of policy issues, the *“superior design features of newer facilities”* was noted and that *“the positive impact of these could be seen” (R23)*, but that dementia friendly design was still not the norm and it should be. Several respondents raised the need for small scale facilities embedded in their communities and the need to stop building *“large scale ghettos on the edges of cities” (R14)*. It was suggested that people with dementia and other users of nursing homes be much more involved in the location and design of nursing homes and that universal design principles should be standard.

Several respondents emphasised the need for a range of options; better funded home care and other options; so that nursing homes are not the only option and that in some sense nursing homes should be *‘the last resort’*. The need for a more appropriate funding model which would meet psychosocial needs as well as care needs was also referenced; *“Nursing homes are paid to prescribe medication including anti-psychotic drugs to residents with dementia but there is no equivalent budget to deliver on therapies such as reminiscence, life story work, pet therapy, and so on. The value of non-pharmacological interventions need to be acknowledged and nursing homes appropriately reimbursed for their use” (R08).*

In considering the future roles of nursing homes in the context of a more fully developed continuum of care there are somewhat conflicting drivers, where in one direction we are trying to constantly reduce length of stay, focusing on people with high needs and maybe even a palliative-care/end-of-life orientation, while in the other direction we are trying to make them feel and operate more like a home. A potential future vision for nursing home facilities was one which would feature *“award winning buildings and physical environments, with integrated care*

*and funding systems linked into the development plans of the local authority so that other social and commercial infrastructure can be developed around it. ...the objective should be to show the potential for such facilities to maintain people at home through outreach and respite as well as acting as a home and [providing high intensity care]... when required” (R16).*

The role and provision of specialist care units (SCUs) for people with dementia living in long-stay care facilities was also considered in the survey. About one fifth of stakeholders had little or no experience of SCUs and did not answer the question asked on SCUs. For those that did respond, there were mixed views on its role and provision within long-stay facilities. Most respondents felt there was a need for specialised facilities with highly trained staff who could provide care for people with very complex needs, particularly if there was a psychiatric component and/or severe responsive behaviours. It was also recognised that these units can offer an opportunity *“for better staff training and education with regards behaviour and distress associated with dementia...”* (R25). Many respondents stressed that this specialist level of care was only necessary for a minority. One suggestion was that specialist units; *“Should be planned and designed to accommodate needs on a regional basis with appropriate support from Geriatrician and Old Age Psychiatrist”* (R23). Some respondents felt that the SCU does not necessarily need to be a permanent placement; *“Many people requiring this type of care will not necessarily need it for a prolonged period and with good care can transition to environments where they might need some extra supports but are essentially cared for as part of the normal LTC environment”* (R23). It was also acknowledged that mixing people with different needs together in large scale units is not good for any of the individuals involved: *“there is a major problem for older people who do not have dementia, and younger people inappropriately placed... who have no choice but to live among large numbers of people with advanced dementia. From their perspective this is not just challenging; it may make their life unbearable”* (R16).

Alongside this acknowledgement of the need for SCUs for a small number of people with dementia, there were concerns about segregating people, about *‘over-medicalising dementia’*, and that *“many are overly focused on security and risk reduction rather than life-enhancement”* (R25). There was a view that; *“if all gerontology staff were trained and all buildings were designed to be dementia friendly then there would be no need for segregated units”* (R31).

### **Barriers to the Development of Alternative Care Settings**

There were very detailed responses received describing many barriers to the development of alternative care settings. The most commonly cited barriers were:

**Funding models** (13 responses) - *“there is a lack of cross-agency, cross-departmental financial or other appropriate funding models to incentivise this type of provision”*. The financial sustainability or viability of alternative models was noted by several respondents with alternative models seen as *‘not commercially viable’*. There was also a need to identify the correct balance of funding between self-finance, co-payment and state support. As well as the lack of funding models to support alternative care, the lack of funding in itself for care for older people and people with dementia was noted by several respondents, with nursing home care in effect being incentivised as it had a clear funding model and a ring-fenced funding source.

**Non-supportive attitudes** (8 responses) - *“there is still a negative attitude to housing for older people and it is often seen as a burden rather than a potential benefit to a town or city. This can hamper integrated approaches and innovative initiatives”* (R09). Underlying stigma and negative attitudes towards older people in general and people with dementia in particular were described as hampering the development of alternative care models for people with dementia, with older people being seen as *‘low priority’* particularly in the current climate where they can be seen as *‘competing for a scarce resource’* (i.e. housing).

**Lack of policy direction** (8 responses) - in terms of national policy *“there is a fragmented approach to alternative care settings and a lack of a cohesion between housing, healthcare, long-term care”* (R09), with *“multiple stakeholders... a disjointed approach... and a lack of clear leadership at government level”* (R25).

**Culture/Tradition** (5 responses) - It is recognised that there is a lack of familiarity with alternative care models in Ireland and that it is *“hard for people to imagine these until they have seen them”* (R23) and that *“we don’t have a wide range of care options available to people with dementia in Ireland. Traditionally it has been care at home or in nursing home. There are not many examples, or expertise, within the Irish context in which to draw on”* (R13). It was noted that we need to create a culture where *“movement to alternative care settings is an acceptable and more positive consideration for citizens”* (R05).

### **Developing the Continuum**

Respondent were asked to describe government actions that are needed to facilitate the development of alternative care settings between own home and residential care for people with dementia. Most of the responses were under three main headings; funding, coordination and policy/legislative changes. The need for more funding and for sustainable funding models was the most frequently noted action. Related to this was the need for a range of incentives for different models and different stakeholders such as developers, local authorities and the person/family. The need for coordinated action was another key action as *“the issues bridge the domains of health and well-being, and local government planning/housing and community development, this converging agenda really needs to be pursued on a cross-departmental basis”* (R17).

If alternative care models are to be developed, supportive policy and legislative changes will be required. Respondents identified some of the changes that will be necessary, such as putting *‘home care on the same footing as residential care’* and *‘policies should be developed in a coherent and integrated fashion that recognises the broader needs of an ageing population, ...including those with dementia’* (R05). Policy-makers and legislators need to engage with the complex issue of private and public responsibility for care provision and funding, as well as mechanisms for harnessing collaborative efforts to develop innovative solutions; *‘There is no effective legal or systems underpinning for models of ownership based on mutuality and cooperation and the sharing of public and personal resources in the context of support, care and housing. This is not about getting NGOs, the HSE and local authorities to collaborate; it is about people themselves being facilitated to collaborate in joint initiatives and having greater say over how support and services are provided’* (R16).

The need to build the evidence base and demonstrator models was described by several respondents: *“foster an array of social policy experimentations to examine which (of a range of) models might work - or alternatively create the conditions for a wider range of options and choices to flourish. We need to explore; Financial innovation; Place-based innovation; Care-model innovation, but these need to be pursued in an integrated fashion”* (R17); and to develop *“exemplar models which are financially sustainable and attractive alternatives. People should want to live there; not just live there because they need to”* (R25). These actions could potentially: *“Support the development of an evidence-base to provide guidance on alternatives to traditional models of long-term care before embarking on costly capital projects to develop new approaches to care”* (R13). Greater awareness and education among local authority personnel on planning and housing design for older people/people with dementia, including the availability of planning and design guidance was identified as a key enabling action. One concrete way to make progress was to form; *“Local planning groups to identify areas most suitable for these developments involving healthcare providers, local authorities and focused representation for [older people] in the community”* (R25).

## Conclusion

It is clear from the survey responses that there is a strong, shared understanding of ageing in place and that this should be supported in a more proactive and diverse manner than heretofore. A strong consensus which emerged through the survey responses is that the major part of the continuum of care is really about evolving and promoting various manifestations and models of home; staying at home through the provision of a greater amount and range of home supports; making the process of adapting a home much easier; avoiding the need to adapt through better initial housing design and planning into the future; and providing well-designed, attractive, community-embedded forms of supported housing. Respondents provided well-developed descriptions of these options with a consensus that this is the way forward.

There was little support for the dementia village form of provision, with strong concerns about segregation and institutionalisation expressed. However, in a future context of a well-developed continuum of care that offers many different options for people with dementia, as described above, then dementia villages could potentially be one of these options if a person expresses a clear preference for this type of arrangement. However, given the fact that this type of development is at variance to national policy in a number of areas (e.g. disability policy), the use of public funding to incentivise or fund this form of provision would need careful consideration. As was noted by one respondent to the survey *“while conceptually interesting and having potential for aspects of it to inform housing and neighbourhood design it is not something worth copying at such scale in Ireland. Why would we be closing congregated settings for people with intellectual disabilities and opening them for people with dementia?”* (R16).

There is a recognised need for the higher levels of support offered in nursing homes and the more specialist support available in SCUs. The thrust of the survey responses was that the principles of dementia friendly design and community orientation extended to these facilities as well, in the sense that they need to become ‘home’ for people who reside there. With the development of a richly populated continuum of care, with a well-funded home care model, adapted housing and a range of other options to suit different preferences, we may well see the role of the nursing home change. These settings may become more closely identified as step down facilities from acute care, where high levels of nursing care and even palliative care are provided. In this sense, a nursing home really will be the ‘end of the continuum’ although this type of change is likely to take several decades. In so far as we might continue to need nursing homes and public long-stay facilities in the future we will need to reconcile the emerging tension between different drivers. In one direction we are trying to continually reduce average length of stay where nursing homes places take-on a more palliative-care/end-of-life orientation. In the other direction, evidence suggests that a small scale, home-like environment is best practice for some people with dementia, who can no longer live without significant levels of nursing care. However, these may not be irreconcilable options, given good design, sufficient physical space and appropriate funding.

If we are to develop a richly populated continuum of care to make ‘ageing in place’ a reality, greater integration and collaboration is required between government departments and agencies. The recent publication of a joint policy statement on Housing Options for Our Ageing Population by the Department of Health and Department of Housing Planning and Local Government (2019) is a welcome step in this direction. Legislative and policy changes are required which, for example, places funding for home supports and residential care on the same footing. Greater creativity and responsiveness is also required in terms of funding models; innovation needs to be supported by appropriate funding models, beyond current arrangements, including, for example, personalised budgets for some people with dementia. As one respondent noted: *“If the financial models can be more innovative, perhaps our ‘place-based’ interventions may follow suit!”* (R17). The following quote sums up the general mood among stakeholders: *“‘Home First’ should be the key policy mantra but there needs to be real dialogue around what’s needed to achieve this and the positive personal, economic and social dividends if properly applied”* (R23).

# Chapter 9: Developing the Continuum in Ireland

## Introduction

Making sense of the continuum of care for people with dementia is difficult. Ideally, people with dementia will continue to live at home after diagnosis, receiving appropriate care and supports as the disease progresses, up to and including end-of-life care. This is what most people with dementia want and it is the principle underpinning practice and policy in the country. But, of course, the reality for some people with dementia is very different. The community care system is not always able to deliver the care that people need to remain in their own homes. The lack of alternative care settings along the continuum means that the only 'choice' available to significant numbers of people with dementia in these circumstances is residential care.

The continuum of care has the potential to take away the binary choice between home care and residential care and provide alternative options for people who can no longer live at home. The continuum incorporates many different settings and forms of living including adaptation to the family home, housing with care and small scale independent living within residential care environments. There is no science that accurately predicts when a person with dementia should leave their own home for a different care setting. There are predictors that make a move more likely, for example, the absence of informal care, people living on their own, poor housing, co-morbidities, behavioural problems and acute illness, but the costs and benefits of moving are likely to be unique for every individual. In addition, preferences matter and supported housing options that suit one person may not suit another.

Furthermore, moving people with dementia from one setting to another may cause significant dislocation and disruption - the very antithesis of ageing in place. Therefore, in providing greater choice of settings for people with dementia, we should not lose sight of the fact that people prefer living at home and policy must, in the first instance, focus on making sure that people can continue to live at home as the disease progresses. The continuum should offer choice, but only when living at home is no longer viable and preferences always need to be respected. Moreover, there is no argument for moving people with dementia continuously across the continuum in the search for short-term solutions or less expensive options.

## The Voice of People with Dementia

Living with dementia is a highly individualised and emotional experience, irrespective of where care is provided. Thus, it is very important to involve people with dementia directly in decision-making about their own care preferences and experiences. The Assisted Decision Making (Capacity) Act 2015 (ADM Capacity Act) creates the right for a person whose capacity may be in question to be supported to make their own decisions, and there is an obligation to fulfil this right. The Act states that a person *'shall not be considered as unable to make a decision in respect of the matter concerned unless all practicable steps have been taken, without success, to help him or her to do so.'* The Guiding Principles of the ADM Capacity Act include the presumption of capacity and the requirement that a person *'should be given all possible support to make their own decision. This means that all relevant information about the decision is given to the person in way that is appropriate to their own circumstances, considering the persons means of communication, the time and place that best suits the person, and using appropriate communication aids to assist the person'*.

The analysis of various systematic reviews for this report reveals three key requirements for people with dementia, irrespective of care environment: maintaining personhood; enhanced connectivity; and the opportunity to lead purposeful and meaningful lives. People with dementia want to be valued for who they are; they want to be connected to family and community; and they want to live meaningful lives, even if that life is different to the one they had before the onset of dementia. Making sure that people with dementia maximise quality of life is, therefore, important along all points on the continuum of care. Listening to, and hearing from people with dementia is a necessary pre-requisite to developing the continuum of care in Ireland (Donnelly *et al*, 2018). People with dementia want the right care (appropriate to their needs and that respects their preferences), delivered in the right way (person centred and integrated), at the right time (in context of the stage of disease), and in the right place (a range of alternatives). Crucial to getting 'it right' is prioritising the voice of people with dementia in the decision-making process. This fact is important to remember as we examine different models of care along the continuum for people with dementia.

### **Stakeholder Views on the Continuum**

Stakeholders provided a rich understanding of ageing in place that centred on the role of people, communities and the environment in contributing to a good life for people with dementia. Home was the dominant theme among most stakeholders. Universal design, adaptation and appropriate supports, both individually and in combination, were considered the immediate priority for ensuring that ageing in place could take place. There was consensus that ageing in place should not be determined by the current post code lottery system that continues to influence access/eligibility in relation to primary care, social care and acute care. When people were no longer able to live at home, stakeholders referenced choice and autonomy in respect of decision-making about alternative placement. They wanted people with dementia to have a strong say in both the location and type of care provided.

Stakeholders recognised the potential value of housing with care solutions, but equally recognised that supported housing may not suit everyone, particularly if it separated people from their families and local communities. Housing with care solutions should not take people out of their local environment, detached from familiar people and landscapes. If anything, people with dementia should become even more embedded within local communities through supported housing schemes. Similarly, new housing with care models should be integrated into existing social care structures, with services and supports provided on-site or close by. Some stakeholders were concerned about what happens when people have to move from housing with care to traditional residential care, worried that an additional move could be traumatic at a time when people were at their most vulnerable. Stakeholders felt that a sense of place still matters for people with dementia and that not enough is currently being done to foster attachment and belonging in either public or private long-stay facilities. Close connections with the community and the opportunities to maintain social networks are important for people with dementia. Neighbourhoods matter as much as buildings for people with dementia.

Stakeholders wanted smaller scale, homelike residential living facilities for people with dementia, where independence is valued, autonomy is protected and care is personalised. Stakeholders were of the view that keeping people independent should be the goal of residential care as much as community care and that small-scale living could support this objective. However, respondents also recognised that the vast majority of people with dementia in Ireland are being cared for within generic care facilities for older people, most of which are not purpose-built for dementia and many of which are not designed to offer independent living for residents. Some stakeholders welcomed the fact that all new nursing home builds now have to incorporate dementia specific design principles, the benefits of which will permeate the whole system in due course. And there was an acknowledgement that many existing nursing homes have made significant improvements that promote universal design principles and the built environment.

When stakeholders talked about the development of the continuum and policy for the future almost all emphasised the importance of joint, integrated action between health and housing. That joint action requires interdepartmental co-operation between the Departments of Health and Housing, followed by closer working relationships between the HSE and the Local Authorities. Joint funding models were identified by stakeholders as crucial to developing new housing initiatives for people with dementia. Demonstrator housing projects were also highlighted as being very important in showing the value of co-operation; these can be funded through public-private partnerships and philanthropic support. Some respondents counselled that stigma towards dementia may still permeate housing agencies and care agencies, creating a risk averse environment that makes change more difficult than it should be.

### **Principles for Change**

Five key principles for change can be distilled from our analysis of the dementia literature and the stakeholder consultations: ageing in place; personhood; choice; autonomy; and connectivity. Two of those principles: place and connectivity, overlap with those used to inform the recent *Policy Statement on Housing Options for an Ageing Population* produced by the Department of Housing, Planning and Local Government and the Department of Health (2019). People with dementia should age in place wherever possible, allowing them to live close to family and community. This further reflects two other principles used to guide the recent government *Policy Statement*, namely sustainable lifetime housing and assistive technology. New public investment reflecting these principles would help to ensure that the movement of people with dementia along the continuum of care is done sparingly and not at all, wherever possible. Multiple moves for people with dementia across settings would certainly be avoided, if these principles were reflected in future policy for people with dementia. If people have to move, housing and care should be integrated in a way that allows ageing in place to continue, maintaining attachments and relationships among people and places that enhance quality of life within vibrant age-friendly communities.

Personhood is already an over-arching principle for the National Dementia Strategy. In relation to the continuum, it should be used to support identity and protect the self through an expanded ageing in place strategy. That is mainly achieved by supporting living at home, but if not, it requires the tenets of personhood to be respected and reflected in other settings. Choice is the key to understanding investment along the continuum of care for people with dementia in Ireland. Whenever people with dementia are asked about where they want to live, they usually say in their own home. Similarly, when citizens are asked to speculate about where they would prefer to live in their older age, the vast majority say in their own homes. That choice should be respected through public support for home adaptation and personalised home care provision. But some older people may choose to live in supported housing schemes and that choice may also need support through tax incentives and new regulatory procedures.

People also want autonomy wherever they live. That means supporting people to live privately and independently whether they live at home, in supported housing or in residential care. Many people with dementia can continue to live well in independent settings, supported by care services and supports but not defined by them. Connectivity is also important, meaning that people with dementia should be connected to people, places and communities wherever they live. Once again that is easier when people live at home, but not impossible if they live elsewhere. This has implications for location, proximity, design and staffing in both supported housing and residential care settings. An optimal continuum of care requires the continued engagement of people with dementia in decision-making, discourse and activities, in accordance with preferences and capabilities.

## Developing the Continuum

Maintaining people in their own homes should continue to be the key goal of policy for people with dementia in Ireland. Personalised care, whereby the needs of people with dementia are addressed in an individual way through the provision of a co-ordinated care plan, is central to keeping people in their own homes. Unfortunately, as some stakeholders point out, personalised care is only developing in Ireland and integrated care is equally weak, especially across the health, social care, housing and environmental sectors. Integrated care is very important at times of transition for people with dementia, for example, following diagnosis, acute illness, falls, co-morbidities, behavioural changes and excessive carer burden, when needs change and responses must be immediate, co-ordinated and flexible. Therefore developing the continuum requires significantly more investment in home care provision for people with dementia. In legitimately seeking other solutions along the continuum, it is important not to forget that fundamental point. It is heartening therefore to see six actions outlined (Actions 5.1 to 5.11) in the *Policy Statement on Housing Options for an Ageing Population* (Department of Housing, Planning and the Environment and Department of Health, 2019) that will, if followed through with new regulation and enhanced financial resources, support the fundamental objective of maintaining older people in their own homes for longer.

Home adaptations should be incorporated into decision-making and joint funding models for the development of home care solutions for people with dementia. Home adaptation can be as important as home support hours for people with dementia in keeping people living well in their own homes for longer. In France, home adaptation for people with dementia has developed significantly in recent years to fulfil obligations outlined in successive National Alzheimer plans; people with dementia can have their homes assessed to see if adaptation could be beneficial. This approach needs to be part of the post-diagnostic support system in Ireland, with mandatory access to timely assessments of the living environment of people with dementia. The assessment, application and funding process should be integrated across health, the local authority and other relevant agencies to ensure the process is as easy as possible for the person.

The process of applying for financial support for home adaptation in Ireland is costly, slow and cumbersome. There are identification lags, process lags and implementation lags, all of which serve to lengthen the time between the identification of a problem and finding a solution that supports independent living at home. An absence of knowledge and information among practitioners on the role and importance of good housing design in dementia care means that it may take years even to identify what needs to be done to improve housing, even simple changes like signage, bathrooms, doors, lighting etc. The application process for grant approval also takes time and even when it is granted some people may have to move temporarily from their homes to allow renovations to occur. This can be a major logistics problem for those that do not have family, leading to further process lags as alternative temporary accommodation has to be found by the HSE. Implementing the modifications can also take time as builders have to be sourced and contracts agreed and signed.

Some stakeholders referenced the importance of earlier solutions to housing adaptations, suggesting that design issues start when the house is initially built. While we cannot do much about past legacy issues, there is an urgency to incorporating universal design elements into new house constructions. Universal Design can help people adapt to change across the life cycle by factoring in at the outset key design features that respond flexibly and seamlessly as the person ages, including being able to respond to dementia issues in later life. Action 3.4 of the *Policy Statement on Housing Options for an Ageing Population* (Department of Housing, Planning and the Environment and Department of Health, 2019) supports this approach promising to ‘develop a design for life rating mechanism for homes that will ensure the energy-efficiency and age friendliness of homes to enable them to be truly sustainable’. Any design principles should take explicit account of the possibility of dementia in later life.

Keeping people in their own home is easier when they have the support of families and the broader community. People with dementia living on their own, or isolated, geographically or socially, from family, friends or community are more likely to end up in residential care, according to stakeholders. Supporting the medication, nutrition and hydration needs of these people can be very challenging, as can meeting their social needs. This opens up the possibility and desirability of supported housing with care options for people in these circumstances. Some stakeholders were of the view that housing with care works best for those at a relatively early stage of dementia, who are otherwise healthy. Others were less cautious and felt that the most important thing was to ensure that people in this setting had access to appropriate care, including psychosocial supports, irrespective of the stage of the disease. One of the key difficulties is that the current language and organisation of care separates health and housing rather than seeing them as unifying concepts influencing overall well-being and quality of life. Closer collaboration between the HSE and the Local Authorities is essential, therefore, in making housing with care a realistic alternative for some people with dementia. Action 3.2 of the *Policy Statement on Housing Options for an Ageing Population* (Department of Housing, Planning and the Environment and Department of Health, 2019) is encouraging in this regard, promising to ‘*mandate consultation between Local Authorities and the HSE as part of the planning process in relation to supported housing developments and identify policy in relation to planning for support services (home support) in advance of commencement and development*’.

Long-term residential care is often the most appropriate care option where an older person’s needs are complex. However, there is evidence from our consultation with stakeholders of strong support for much smaller scale, homelike developments, with provision for autonomous, independent living within long-stay environments, in addition to conventional clinical/nursing/end-of-life capacity. The current system of long-stay care in Ireland remains conservative, custodial and medical in orientation. This must change, not least because it is not good for residents or staff. The built environment can play a significant role in supporting nursing staff in integrating residents with dementia into their daily nursing tasks, providing additional stimulation and connectivity for both parties (Lee *et al*, 2016). Physical characteristics, such as unit size, spatial layout and having an outdoor area have been linked with the achievement of therapeutic goals of awareness, orientation, functional abilities and social contact for people with dementia (Chaudhury *et al*, 2018). This has led de Boer *et al* (2018) to conclude that the physical environment of small-scale, homelike nursing homes has more potential to be beneficial for people with dementia than traditional nursing homes. Hence, the need for regulatory and financial interventions to encourage supply-side changes in the built environment within nursing homes in Ireland. Only one action in the *Policy Statement on Housing Options for an Ageing Population* (Department of Housing, Planning and the Environment and Department of Health, 2019) deals with residential care - Action 4.12 which calls for planning guidelines to be issued ‘*for the development of residential care homes and primary care centres to ensure that they are appropriately designed and located in areas with access to transport and amenities*’.

There are many good examples of supported housing models and small scale residential care provision in other countries that serve as an alternative to traditional long-stay care facilities. Japan leads the way in terms of planning for housing needs, sheltered accommodation and resident-friendly care homes. Group homes now provide an alternative to the traditional residential care model in that country. In the Netherlands, small-scale living facilities are now part of the mainstream delivery of dementia care. In Denmark, the parliament passed legislation in 1987 which stopped the construction of the old-fashioned nursing-homes, instead introducing modern nursing home apartments, usually with two rooms, kitchen and bathroom. Many old nursing homes in that country have been rebuilt to fit the new concept of ‘*close-care accommodation*’, with a permanent staff to service and support the people living there. The separation between residential care and nursing care has long been a feature of the provision and funding of long-stay care in the UK. For all of the examples that exist, however, there is still not near enough evidence on their impact on the health and well-being of people with dementia. This has led the OECD (2015) to conclude that a model of care that promotes greater control and social interaction for people with dementia may be more important than the location, scale

or size of the setting. It is hard to disagree with this conclusion, given what we know about what people with dementia want most from the care system - to remain living at home, close to family and community, with as much independence as possible.

### Policy Recommendations

As people age, their housing needs are likely to change, particularly following a diagnosis of dementia, but every effort must be made to ensure that people remain in their own home for as long as possible and practicable. This can be done through the provision of appropriate levels of personalised home care and through universal design, sustainable lifetime housing, and house adaptation programmes that are timely, accessible and appropriate. For people with dementia who need supported housing with care provision, the principles of personhood, choice, autonomy and connectivity are even more relevant. Multiple moves across the continuum should be avoided, but if and when long-stay care in residential facilities is required, it should be provided in small-scale, homelike units that preserve the personhood of the resident. The recommendations outlined below are specific to dementia, but complement the recent universal actions on housing for older people proposed by government in their recent Policy Statement (Department of Housing, Planning and Environment and Department of Health, 2019).

1. Maintaining people in their own home should continue to be a key goal for people with dementia in Ireland.
2. People with dementia must be involved in decisions around their care. The full commencement elements of the Assisted Decision Making (Capacity) Act 2015 such as the Decision Support Service will provide a legislative underpinning for the necessary support to enable people with dementia to be involved in decision making.
3. People with dementia should not be required to make multiple moves to access different levels of support. As far as is practicable, supports should come to the person, including home support services, assistive technologies and housing adaptations to facilitate ageing in place.
4. Home care should be expanded and enhanced as the key strategy in the development of the continuum of care for people with dementia. The provision of additional personalised services and supports for people with dementia living in their own homes should be prioritised above financial support for any other care setting, especially residential care.
5. Lifetime universal design should become standard for new housing stock, including nursing homes and public long-stay facilities.
6. The home adaptation scheme should be simplified, expanded and managed better for people with dementia. The scheme should incorporate mandatory access to an assessment of the home/living environment for people who have been diagnosed with dementia.
7. Consideration should be given to the development of multi-stakeholder models at CHO level which integrate the required elements for a timely and tailored response for home adaptations, including health professional assessment, design specialists, budgets, funding approval and contractors.
8. An adequate supply of a range of housing options should be available at a designated geographical level in order to provide for the preferences and needs of people with dementia as they age. For planning purposes this geographical area could be CHO with co-terminus Local Authorities.
9. A number of organisations need to work closely together in order to further develop supported housing options. Structures to enable formal inter-departmental and inter-agency co-operation should be put in place. This cooperation should include joint funding arrangements, and should facilitate enhanced co-operation among health agencies, Local Authorities, private care providers, housing associations and community and voluntary sector organisations.

10. Demonstrator housing with care schemes for people with dementia should be established to support and test joint financing arrangements and integrated care provision. An evaluation component should be part of any new demonstrator schemes.
11. All new supported housing with care schemes for people with dementia should be built in central locations and embedded within local, inter-generational, communities.
12. Maximum use should be made of assistive technologies to enable people with dementia to remain independent for as long as possible and to enhance their care and quality of life, whatever setting they are in.
13. Dementia villages are only slowly evolving internationally, so further evaluation is necessary before making decisions on any new investment in this type of setting in Ireland. New dementia villages should meet the principles of: place; personhood; choice; autonomy; and connectivity.
14. Following the development of supported housing options and the provision of greater levels of home support services, there is potential in the future for nursing homes to have a far greater focus on the provision of clinical, nursing and end-of-life care.
15. A Continuum Review Group should be established to examine resource use, balance of care, housing infrastructure, dependency, dementia bed capacity and funding requirements across the whole spectrum of care for people with dementia.
16. Future investment in nursing home facilities must incorporate universal design principles and dementia-specific design and should provide small scale, homelike residential living facilities.
17. Funding, incentives and regulatory structures should be adjusted to take account of the realities of growing and developing the continuum of care for people with dementia in Ireland, especially in relation to developing different types and mix of residential provision.

## Chapter 10: Conclusion

The key to the ongoing development of the continuum of care for people with dementia is an increased level of funding for Home Support services for those living in their own homes. In addition, more resources for home adaptation will yield significant short-term gains, while a focus on universal lifetime housing will yield significant gains in the long-term. New housing with care schemes will also provide an alternative to residential care for a small but significant number of people with dementia, particularly those without family carers and those living in isolated areas. The opportunity now exists to realise these objectives following the publication of a Policy Statement on housing for an ageing population produced by the government in recent months (Department of Housing, Planning and the Environment and the Department of Health, 2019). Our report was written simultaneously to, but separately from, the Policy Statement but many of our recommendations mirror the fifty two action points outlined in the Statement. We have said more about the need to recalibrate residential care towards small-scale, homelike environments, but the thrust of both reports are similar, even down to the underlying principles.

It is what happens next that is important for people with dementia. There has been a welcome policy focus on people with dementia in recent years, mainly arising from an external engagement by the Atlantic Philanthropies in dementia in Ireland, through their philanthropic funding of research, practice and service provision, including support for the National Dementia Strategy. That period of support is now over and we are, once again, solely dependent on the Exchequer to support the action points contained in the Policy Statement on housing and the recommendations contained in this report. The next phase, therefore, is about policy implementation if we are to realise the actions that we all know are necessary to transform the lives of people with dementia.

There is robust evidence to support public investment in ageing in place, universal design, enhanced home support services and targeted home adaptation for people with dementia. There is emerging evidence that housing with care can be a good solution for some people with dementia, provided that it is co-ordinated, integrated and located within familiar landscapes and communities. New demonstration models can provide us with better information on what works best for people with dementia in Ireland. The final piece of the jigsaw is generating support for a new kind of homelike residential care experience that is focused on independent living for people with dementia with opportunities for engagement, interaction and meaningful activities. However, none of this will happen without the political leadership to recalibrate the care system and deliver the necessary resources to achieve what people with dementia need, want and deserve. If we remain faithful to the twin principles of the National Dementia Strategy: personhood and citizenship, we can develop a continuum of care that provides choice, autonomy, independence, connectivity and inclusion for people with dementia. Not to do so would be a breach of trust and promise.

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# Appendix

## Ten Questions on the Continuum of Care for People with Dementia in Ireland

- Eamon O'Shea

### **Background**

The National Dementia Strategy commits the HSE to examine a range of appropriate long-term care options to accommodate the diverse needs of people with dementia, including housing with care options.

I am currently undertaking a review of the continuum of care for people with dementia for the National Dementia Office which will examine various settings between living at home and living in residential care/nursing home facilities in Ireland. These settings include: adaptive housing; housing with care/supported independent living; dementia villages; small group living facilities; specialist dementia care units; and any other relevant settings. The review will provide evidence to support the HSE to develop appropriate care models for people with dementia into the future.

### **Your role**

An important part of the review involves eliciting the views of a small number of key stakeholders on the continuum of care for people with dementia in Ireland. I have identified you as a key stakeholder who may be interested in contributing to the review through the completion of a semi-structured questionnaire.

The following open-ended questionnaire allows you the opportunity to provide insight on the continuum of care for people with dementia in Ireland, including consideration of the facilitators and barriers to change. Your response will help me shape the narrative of the review, but you will not be identifiable in any way in the final report.

There are no right or wrong answers. Moreover, while I value your response to all questions, feel free to only answer those that are relevant to you. I also appreciate that what I am asking is an imposition on your time, so you can be as succinct as you wish in your responses. You are, of course, not obliged to contribute at all and, therefore, you may decline, without explanation, the opportunity to complete the questionnaire.

### **Closing date**

Please return the questionnaire to me (eamon.oshea@nuigalway.ie) by 31 January 2018.

# Continuum of Care Questionnaire

1. What is your current position/role in dementia care in Ireland?

2. What do you understand by the term *ageing in place* with respect to people with dementia?

3. What are the key barriers that prevent people with dementia remaining in their own homes for as long as possible and practicable, including the built environment, if relevant?

4. What are the key issues in respect of *adaptive housing* (repairs, improvements, modifications) for people with dementia who want to remain in their own homes?

5. Sometimes it may make sense for people with dementia to move from their current home to live in more supported accommodation. This is sometime called *supported living*, *Housing with Care*, or *independent living* with care facilities, for example Anam Cara Housing with Care in Dublin, or Radius Housing with Care in Belfast. What are your views on this kind of accommodation for people with dementia?

6. *Dementia villages* have been put forward internationally as an alternative to residential care for some people with dementia, for example, Hogeweyk in The Netherlands is a specially designed village with 23 houses for 152 people with dementia <https://hogeweyk.dementiavillage.com/en/>

What are your views on the concept of the dementia village and its applicability in Ireland?

7. What are the most important practice and policy issues in relation to the *future care* of people with dementia in *nursing homes and public long-stay facilities* in Ireland, including the built environment, if relevant?

8. What are your views on the role and provision of *specialist care units (SCUs) for people with dementia* living in long-stay care facilities?

9. What are the *barriers to the development of alternative care settings* between own home and residential care for people with dementia in Ireland?

10. What government actions are needed to *facilitate the development of alternative care settings* between own home and residential care for people with dementia?

Any other comments you wish to make that have not been covered in the previous questions:

Thank you for taking the time to complete this questionnaire.



Eamon O'Shea.



