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# **CREATING EXCELLENCE IN DEMENTIA CARE**

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## **A Research Review for Ireland's National Dementia Strategy**

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# ACKNOWLEDGEMENTS

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## ACKNOWLEDGEMENTS

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## FOREWORD


The estimated cost of formal and informal care for dementia worldwide is currently in excess of 600 billion dollars accounting for 1% of the world's gross domestic product. This cost, which will grow substantially in the years ahead, is a wake up call for governments around the world prompting more and more of them to develop National Strategies for Dementia. The Irish government gave a commitment in 2010 to develop and implement a Strategy which to be effective must be based on reliable research. The purpose of this research review is to provide the data required by collating estimates of current and future prevalence rates, costs and service provision. It also reviews models of local and international best practice placing an emphasis on those which are person-centred and where the individual is treated as a full citizen with accompanying rights. The research review examines the regional prevalence of dementia in Ireland and estimates the increase in numbers over the next thirty years.

This estimation of cost rightly takes both formal and informal care into account, the latter being omitted in many studies. The figures for Ireland match the costs per individual with dementia in other countries and underpin the need for a structured and cost effective approach to dementia in this country. The research review has found that good models of dementia care have been developed in Ireland over the past twenty years but that the level of care provision is very uneven throughout the country with some areas offering little or no support. The review also identifies major deficiencies in the standard of care of individuals with dementia in both acute hospital and long-stay settings. One of the few advantages for Ireland of being a comparatively latecomer in forming a National Dementia Strategy is the opportunity to learn from the achievements and failures of other countries.

The evidence presented in this report will be complemented by direct consultation with individuals with dementia and their carers. This research will ultimately form the basis for the creation of a National Dementia Strategy which should be published by government as planned in 2013. Ireland, rather than lagging behind other European countries as at present, could become an international leader in this field in the years ahead going on to fulfil the aspiration of the Taoiseach, Enda Kenny, to make Ireland "a good place in which to grow old".

Associate Professor Suzanne Cahill, Professor Eamon O'Shea and Dr. Maria Pierce should be congratulated on assembling the highly relevant content of this report. The Atlantic Philanthropies should be acknowledged for having the foresight to fund the work.

Professor Davis Coakley

A handwritten signature in black ink that reads "Davis Coakley". The signature is written in a cursive style with a large initial 'D' and a small dot at the end.

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## AUTHOR BIOGRAPHIES

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## Rationale for the report

Dementia is a progressive condition that largely affects older people, impacting on their memory, language, ability to communicate, mood and personality. The course of the illness may be gradual and sometimes subtle, as is classically the case in Alzheimer's disease. While dementia is a medical condition, recent insights from the psychosocial, socio-political and public health perspectives have focused attention on the human, social and economic implications of the disease. The ageing of the population across Europe and beyond means that the number of people with dementia will grow in future decades with consequent implications for care provision, care burden and public expenditure. It is no wonder, therefore, that many countries are already preparing for the projected rise in the number of people with dementia by putting in place dedicated action plans and/or dementia strategies.

The Irish government has given a commitment in the Programme of Government for 2011-2016 to develop and implement a Strategy for Dementia for Ireland promising to:

*develop a national Alzheimer's and other dementias strategy by 2013 to increase awareness, ensure early diagnosis and intervention, and development of enhanced community based services. This strategy will be implemented over five years.*

The new Strategy has the potential to bring about a major change in public attitudes to dementia in Ireland and to change expectations in regard to the rights of people with dementia. Through the Strategy it should be possible to formulate a plan that emphasises the importance of the person with dementia in decision-making and the role of families and local communities in supporting community-based preferences, wherever possible. It should be possible to develop a plan that will dispel myths, shame and stigma surrounding dementia and enable people to live well with dementia, and promote their autonomy and well-being. It should be possible to develop a Strategy so that people can die in dignity with dementia assured that their complex needs are met by an educated workforce skilled in dementia care and in gerontological nursing and palliative care.

The purpose of this report is to create the evidence-based research that will help to lay the foundations for the new Strategy. The objectives of this evidence-based research review, as agreed between the funders (The Atlantic Philanthropies (AP)), the Department of Health and the contract researchers, were fourfold:

1. to review current and future demographic trends in Ireland and provide estimates of current and future dementia prevalence rates, in relation to both those aged 65 and over and younger people;
2. to specify the main economic costs of dementia care;
3. to review current service availability (based on the recent Health Service Executive (HSE) audit) and estimated future demand for services;
4. to review best practice in dementia care locally and internationally.

Given the terms of reference, not all issues pertaining to dementia could be covered, but the report does provide the basis for the development of many of the areas that will be central to the new Strategy.

## Values

Underpinning this report is a belief that future policy and practice should be influenced and guided by people with dementia and their families. Accepting the personhood of people with dementia requires them being afforded a much more formal role in decision-making at the micro care level and the macro policy level. But for personhood

# EXECUTIVE SUMMARY

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to have real meaning it must be extended into citizenship whereby people with dementia are treated as full citizens with consequent rights and responsibilities. Living well with dementia requires an acceptance by society of the right of people with dementia to live at home in their own communities for as long as possible and practicable. Person-centred care must be a guiding principle and the unique value of the “person” must be recognised in every individual irrespective of his or her level of cognitive impairment. Care needs to be provided in such a way that the person with dementia is valued, respected, treated with dignity and supported to live well with dementia and enjoy a good quality of life. For this to happen, the environment of care needs to be improved through the mobilisation of central and local government resources and local community enterprise to provide the opportunities, services and infrastructure to support the choices of people with dementia to remain living in their own homes.

## Numbers

Prevalence of dementia increases almost exponentially with age, nearly doubling every five years from the age of 65 years onwards. While there have been no comprehensive prevalence studies on dementia carried out in Ireland, the application of EuroCoDe age/gender specific dementia prevalence rates to the 2006 Census of Population in Ireland in this report suggests that there are currently 41,740 people with dementia in the country. An estimated 3,583 of these people (approximately 8.6% of all people with dementia) have early onset dementia and most of these are likely to be men. Our best estimates, albeit extrapolated from a number of uncertain sources, suggest that there are approximately 700 people in Ireland with Down syndrome and dementia.

There is regional variation in estimated dementia prevalence rates across Ireland; Local Health Office (LHO) areas in the HSE West region have the highest prevalence rates of dementia with each of the nine areas estimated to have at least 1% of its total population living with dementia; Roscommon has the highest share of people with dementia in the population at 1.40 per cent. Eastern counties tend to have the lowest share of the population with dementia, with Dublin West having the very lowest share at 0.63 per cent. There are clear regional differences in prevalence rates for dementia and just looking at the age structure of local populations can tell us a lot about the potential prevalence of dementia in that area and the need to structure services accordingly.

The major increase in the number of people with dementia in the country is likely to occur after the year 2021, with the numbers growing to between 141,000 and 147,000 by 2041, depending on assumptions about migration and fertility. In line with the projected growth in the number of the oldest old population, the most marked increase in the numbers with dementia will be amongst people aged 85 years and over. A tentative extrapolation of lower middle-range international incidence rates to the elderly population in Ireland suggests that currently approximately 4,000 new cases of dementia arise in the general Irish population every year.

Our calculations suggest that there are 26,104 people with dementia currently living at home in the community; most of these do not have a formal diagnosis, many are not aware that they have the disease and few are likely to be in contact with the health and social care system. There are an estimated 50,000 family carers in Ireland looking after someone with at least one of six specified symptoms of dementia: for example there are an estimated 25,000 carers looking after someone with marked forgetfulness on a regular or occasional basis, while 15,000 people are looking after someone with confusion to the point of interfering with everyday life. An estimated 14,266 people with dementia live in various public and private long-stay facilities across the country, including 537 people aged less than 65 years. Our estimate of the number of people with dementia in long-stay facilities suggests that 63% of all long-stay residents have dementia.

This study has estimated the overall cost of dementia in Ireland to be just over €1.69 billion per annum, 48% of which is attributable to an opportunity cost valuation of informal care provided by family and friends to those living with dementia in the community. A further 43% is accounted for by residential long-stay care, while formal health and

social care services contribute only 9% to the total costs of dementia. The average cost per person with dementia in Ireland is estimated at €40,500, which is consistent with per capita estimates from other countries.

## Needs and gaps in service provision

In Ireland, early diagnosis, and sometimes any diagnosis, is the exception rather than the rule. The public need much more information on the disease and its implications, thus creating higher expectations in regard to care pathways, including preventative strategies. Further investment in memory clinics would widen and deepen diagnostic services. But equally important are targeted multi-disciplinary education and training programmes for primary health care professionals, designed to equip them with the necessary skills to diagnose dementia, or, at least, to know enough to be able to refer people to facilities that could provide more comprehensive diagnostic information.

In reviewing the research evidence for this report, a substantive body of published literature was found, demonstrating that caring for a person with dementia compared with other caring roles, places much greater demands and strain on family members. Carers want to care, but would like more relief and more support from the ongoing burden of care. They also want to be more involved in the process of caring, including making decisions about the most useful services needed to help them in their caregiving roles. They are the experts and have an enormous amount to contribute as they are familiar with the past history and biography of the person they care for and many have become very resourceful in developing their own strategies for coping with the excessive demands of the dementia care role.

The evidence from this study confirms that community support services for people with dementia and their carers are under-developed and fragmented in this country. The baseline profile of community services is low and only a small proportion of people with dementia are known to service providers. Generally, people with dementia do not come into contact with the health and social services, until a crisis occurs involving the person with dementia, their carer, or both parties. One of the resounding weaknesses of Irish statutory home care services compared with those developed and delivered in other countries is that these services are not underpinned by legislation and are not provided on a statutory basis. In the absence of the required level of community support, people with dementia will continue to be placed in long-term care prematurely.

Our view is that the best way to ensure that people get the services they need is to develop a system of case management for people with dementia and have available 'dementia champions' to assist and support people in their journey through the disease trajectory. In this country, very few people with dementia have been allocated a case manager or even a key worker to directly represent their interests as consumers and citizens. A case manager would facilitate needs assessment, oversee the development of a care plan, co-ordinate the delivery of public, private and voluntary services and monitor outcomes at a community level, including the transition to and from hospital. A case manager would be a person whom the individual with dementia and family members could trust; a key contact person knowledgeable about a whole range of pertinent dementia related issues. This case management approach could be accommodated within the existing framework for health and social services.

People with dementia can sometimes end up in accident and emergency (A&E) departments in acute general hospitals, or as in-patients in these hospitals. Evidence from other countries suggest that some people would not have to be admitted to hospital at all for their particular primary illness were it not for the accompanying dementia. Upon admission to hospital, people with dementia tend to have longer length of stays and poorer outcomes, including higher mortality rates, compared with those without dementia for comparable illnesses. The hospital experience can be extremely frightening and distressing for a person with a moderate to advanced dementia. There needs to be a major review of care for people with dementia in acute settings in Ireland. The development of a dementia champion's programme in acute hospitals would facilitate a more person-centred approach to care and would help to raise awareness of the challenge of dementia. Formal assessment and diagnosis of patients admitted to hospital who might have dementia is a necessary condition for better care and support, including appropriate long-term placement. More

training for general hospital staff to recognise the symptoms of dementia and to provide dementia-friendly care in hospital settings, right up to end-of-life is also required.

Reliable information on the numbers of people with dementia in long-stay settings, including data on the severity of their condition is largely absent in Ireland. Given its statutory responsibility for health information, the Health Information and Quality Authority (HIQA) should provide regular summary statistics on people with dementia, including severity, in all registered long-stay facilities, as well as establishing a register of specialised dementia nursing homes and Specialist Care Units (SCUs) for people with dementia within nursing homes. There is also a need for a new and integrated dementia skills and knowledge programme to guide formal training and education of staff working with people with dementia in residential care settings. This should be provided on a uniform and national basis and available to all staff irrespective of occupational background and linked to ongoing and existing education and training structures. All the evidence suggests that much work needs to be done to change the culture of care for people with dementia in long-stay settings to one of empowerment, dignity and personhood. This should be a major goal of the new Strategy.

## Lessons from other countries

Many countries have now developed action plans and strategies to support investment in infrastructure, administrative systems and services for people with dementia. The various plans that are now available are relatively consistent and convergent with respect to what needs to be done with a common emphasis on: primary prevention; changing private and public attitudes to the disease; diagnosis; improving quality of life and quality of care; training and education for all staff including those in primary care; more day centres and customised residential care; developing timely and appropriate care pathways; and research and policy implementation. Most countries with action plans on dementia have prioritised core areas. For example Australia and Canada have incorporated a focus on primary prevention, on risk reduction and on delaying dementia. In contrast, the Norwegian Plan - Making the Most of the Good Days - places a focus on day care, adapting nursing homes and on increasing public and professional knowledge about dementia. The French approach focuses on a broad range of areas especially raising public awareness of dementia. Scotland emphasises key service delivery systems including improving services after diagnosis, better information systems and improved care in general hospital settings. What each of these countries along with other countries with action plans have in common is an emphasis on the importance of the person with dementia in decision-making and the role that families and communities play in facilitating people with dementia to live well with the disease. Almost all of the strategies have succeeded in generating additional resources for dementia, most noticeably in France, where there has been a significant increase in public investment in dementia care. Dementia, however, continues to lag behind other chronic diseases in terms of budget allocation in most countries, and in the share of resources devoted to research on the topic, particularly relative to disease burden. Developing a Strategy is, however, an important first step generating additional resources for dementia.

## The new Dementia Strategy

This report is not a Strategy for dementia rather its purpose is to inform the development of a new Strategy through the provision of timely secondary research in a number of selected areas. Our brief was to generate relevant and contemporary data to support the proposed new Strategy and provide guidelines as to the future direction of public policy for dementia in Ireland. The report, therefore, does not make formal recommendations as to what should be in the new Strategy, as this would be premature in the absence of a public consultation. Instead, it seeks to provide a coherent narrative of the key elements that might underpin a new approach to dementia in this country based on an extensive review of the national and international literature. Key elements for the new Strategy arising from the research are as follows:

- greater emphasis on primary prevention and on ways of avoiding or delaying the illness particularly in relation to heart disease and stroke

- › enhanced public awareness about dementia
- › early diagnosis through improving access to memory clinics and enhanced multidisciplinary training and education in dementia for primary care workers, hospital staff and people working in long-stay settings
- › case management models of integrated care
- › expansion of dedicated and flexible community-based services, for example, day care services and family support programmes, for people with dementia and their carers
- › development of new and expanded psychosocial approaches to complement existing medical and neurological models of service delivery in the community and in residential care units
- › development of small-scale, appropriately designed, residential care units
- › greater awareness, ownership and leadership of dementia in the acute care sector
- › further expansion and availability of palliative care services for people dying of and with a dementia
- › development of appropriate services for people with early-onset dementia, including people with Down syndrome
- › enhanced information systems on the number of people with dementia, severity of the disease, placement patterns and quality of life

## Next steps

The purpose of this report was to provide the research evidence base for the development of a new Strategy for Dementia in Ireland which has been promised by the current government by 2013. However, while the creation of a research evidence base is a necessary condition for the development of a new Strategy, it is not a sufficient condition. The next stage of the process will require direct consultation with people with dementia, their family members and with all relevant stakeholders to ensure the development of an inclusive and holistic Strategy on dementia that will stand the test of time and will reflect the needs and interests of the key stakeholders. Policy formulation and implementation for dementia requires the direct involvement of the Department of Health and consultation with a much wider coalition of interests and stakeholders than were included in the development of the preliminary research evidence base. That consultation can begin almost immediately given the explicit government commitment that exists for the creation of a new Strategy and the latent goodwill that exists among stakeholders in relation to realising the objectives of any new plan.

There is an understanding now of the primary importance of the person with dementia in any future plan and the role that families and communities play in affecting the environment of care for people with dementia. Given that the economic and social costs of dementia are significant, new investment will be needed to transform the lives of people affected by the disease. In the light of current budget constraints, some of that new investment will have to be paid for through the reallocation of resources within the existing health budget. That is a task for the next stage in the development of a new Strategy for dementia, but it is an important part of consensus building for the creation of a new architecture of care for people with dementia, one that is focused on prevention and with living well with dementia in familiar home settings.







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# CHAPTER 1

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## INTRODUCTION

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“

Dementia affects the whole person: not just the brain and the memory, but also a host of important aspects of daily living.

*Hughes, 2011: 14*

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# CHAPTER 1

## Introduction

### 1.1 Background

Dementia, regardless of its cause, is a progressive condition, with deterioration likely to occur in all domains. It is a distressing and often frightening illness for the individual and can be perceived as stigmatising and heartbreaking for family members. The disease impacts on memory, language, ability to communicate, mood and personality. These and other characteristics on which normal social, occupational and domestic life depends become impaired. The course of the illness may be gradual and, sometimes, subtle, as is classically seen in Alzheimer's disease. It may be more abrupt and can often be characterised by sudden episodes of deterioration as the case in Vascular Dementia, also known as Multi-Infarct Dementia. In Lewy Body Dementia, the course of the illness may be punctuated by episodic confusion, hallucinations and delusions and in fronto-temporal dementia by insidious personality or behavioural changes.

Dementia has no single cause and no cure. Many known and unknown environmental and genetic risk factors can influence the age of onset. Despite a whole myriad of risk factors (including cardio-vascular) contributing to the different dementia sub-types, increasing age remains by far the single strongest risk factor for dementia. Accordingly, people aged 90 and over run a 50% heightened risk of developing a dementia compared with those aged 60. In the past and up until the early 1980s a distinction was made between old-age dementia and Alzheimer's disease - then considered a rare form of dementia affecting younger people under 65. As a result of advances in biomedical research, this clinical and artificial dichotomy between the two types of dementia based on age has now been eroded. Accordingly, whilst about 5% of Alzheimer's disease cases occur in younger age categories, by and large most people who get dementia are aged 65 years and over. Over the age of 65 the prevalence rate for dementia nearly doubles every five years (Lobo et al., 2000).

Nowadays, Alzheimer's disease is said to account for between 50% and 60% of all cases of dementia, followed by Vascular Dementia, which accounts for between 15% and 20% of all cases. Increasingly, many people are being diagnosed with mixed dementia, a form of dementia caused by both Alzheimer's disease and Vascular Dementia. Numerous other causes of dementia exist including Lewy Body Dementia, Frontal lobe dementia such as Pick's Disease, other degenerative diseases such as Huntington's disease, transmissible diseases such as Creutzfeldt-Jakob Disease and HIV-dementia as well as several toxic and metabolic disorders such as alcohol-related dementia. Dementia also develops in between 30% and 70% of people with Parkinson's disease, depending on duration and age (Aarsland et al., 2003). A significant proportion of people with Down syndrome develop dementia in their fourth and fifth decades.

### 1.2 Perspectives on dementia

In the past the dominant paradigm for understanding dementia was the biomedical model: a perspective which concerned itself largely with biological aspects of the illness and focussed exclusively on disease aetiology - causes, treatments and cure. Based on this biomedical perspective, scientific work has significantly increased our understanding of Alzheimer's disease and the related dementias; of the modifiable and non-modifiable risk factors for dementia; of the refined diagnostic guidelines needed by clinicians; and of treatments and interventions aimed at reducing the adverse effects of changes associated with the condition. For example, it has been found that the use of anti-cholinesterase inhibitors may slow down or temporarily improve the progression of dementia, whilst many of the symptoms of Alzheimer's disease, particularly those related to depression, agitation, hallucinations, and delusions, can sometimes be controlled or alleviated by anti-psychotic medications. The biomedical perspective of dementia has clearly played a key role in yielding important insights into our understanding of the causes of dementia, the main signs and symptoms associated with the illness as well as diagnosis and helpful treatments.

In recent years, the influence of the biomedical model has been augmented by the contributions made by several social and behavioural scientists as new ways of thinking about the condition have been put forward including the psychosocial, socio-political and public health perspectives. In this context, the pioneering and revolutionary work in the 1990s of the late Tom Kitwood (a UK-based Clinical Psychologist), who re-conceptualised dementia and rightly argued that people with this condition are a lot more than purely “atrophied brains”, helped to place the person with dementia at the centre stage. He reminded us that people with dementia are human beings whose subjective experience is greatly influenced by contextual, environmental and cultural factors including societal attitudes (Kitwood, 1997; 1998). Kitwood’s recasting of dementia and his broadening of the conceptual lens to include personhood has improved our thinking about dementia and has positively influenced practice and research in dementia care. One of the many consequences of the re-conceptualisation of dementia and this shift in thinking is that creative and valuable research aimed at capturing the perspective of persons with dementia is now beginning to develop. Such research provides invaluable insights into dementia care policy and practice.

Building on Kitwood’s seminal work, other dementia experts have more recently attempted to extend his theory by moving beyond personhood and by arguing that people with dementia are also citizens with rights and responsibilities (Bartlett and O’Connor, 2007). Whereas personhood and the psychosocial approach to dementia led to capturing the perspective of people with dementia, the citizenship model challenges us to regard people with dementia as citizens living within their local communities and within society at large. An advantage of this citizenship or socio-political perspective is that it allows us consider the salient role that public perceptions of dementia play and draws attention to the role of public and professional attitudes in advocacy work and in the care of people with dementia. Hearing the voice of people with dementia is an increasingly important strategy for implementing a social citizen approach to practice. It also signifies that people with dementia can challenge the socio-political status quo and can potentially influence and bring about social change (Bartlett and O’Connor, 2010).

A third and very valuable paradigm for helping us better understand dementia is the public health perspective. This approach places an emphasis on primary prevention, health promotion and on educating and enabling people to take increased control over lifestyle factors which may influence conditions such as dementia. These include modifiable factors such as smoking, alcohol consumption, diet, nutrition and exercise. A shortcoming of this approach, however, is that it tends to put the onus of responsibility for maintaining health very much on the individual. Accordingly, whilst many people can adopt healthy habits to decrease their risk of dementia (such as regular exercise and eating nutritional foods) some of us with exemplary lifestyle habits will inevitably get dementia. It is, therefore, important to recognise that when incorporating health promotion into dementia care, healthy lifestyle is only one of several different factors determining the risk of getting a dementia in later life.

Since dementia is a biological, psychological and social disability, each of the aforementioned perspectives has real merit in helping us gain a more eclectic and holistic understanding of the condition. Multiple perspectives are useful since they enable us explore an illness through different lenses. For the purposes of this research review, therefore, multiple perspectives are used to conceptualise and understand dementia and will underpin the material that is presented in each of the chapters to follow in this report.

## 1.3 Perspectives on dementia care

These multiple perspectives also need to be applied to the everyday care of people with dementia, whether in their own homes, in hospitals or living in some form of residential care. Person-centred care must be a guiding principle and the unique value of the “person” must be recognised in every individual, irrespective of his or her communication difficulties and level of cognitive impairment. Ultimately, care needs to be provided in such a way that the person with dementia is valued, respected, treated with dignity and supported to “live well” with dementia and enjoy a good quality of life. All interventions need to be designed to bring out the best in that person and maximise on his

or her retained abilities. In short, the individual needs to be offered a “first class carriage” (Hoffman, 2006) in his or her journey through dementia with access to only the very best, in terms of quality services, including assessment, diagnostic, health and social care services.

Applying multiple perspectives to dementia care will also involve developing partnerships of trust, understanding and mutual respect between the individual, health service professionals, care workers and family members. High quality support and care of the individual with dementia will only become a reality when true partnerships in care evolve and when the interests of professionals and carer workers are each carefully considered and supported. These partnership arrangements will place the individual with dementia at the centre stage with due regard being given to his or her mental and physical well-being, personality, sense of self, cultural and occupational background, relationships and religious/spiritual needs. At all times, the well-being and autonomy of that individual must be promoted whilst balancing his or her interests with those of the family caregiver. The individual with dementia must be seen as someone with rights and responsibilities who has still much to contribute to society.

Applying such multiple perspectives to dementia care will also mean supporting the individual with dementia from the time of diagnosis, regardless of the availability and usefulness of treatments, to the time of death. It will mean advising that person on lifestyle risk factors which if continued may accelerate or aggravate the dementia. It will mean providing individualised, responsive and flexible social and personal care services, underpinned by values respectful of the individual’s rights and autonomy and maximising his or her well-being. It will mean a commitment to making services flexible, responsive and timely. It will not necessarily mean spending more money, but rather, it will involve listening to the desires, preferences and needs of people for whom the service is being provided and adjusting the support being offered to help them in what they value most (Nuffield Council on Bioethics, 2009).

In reflections and discussions about perspectives on dementia care we are reminded that in writing any report value judgments may arise, thus it is important to state these clearly from the outset. We believe that the broad philosophy and principles that were outlined in *An Action Plan for Dementia* (O’Shea and O’Reilly, 1999) are still valid today and, therefore, are worth restating in summary form, as follows:

- Respect for the personhood, preferences, autonomy and rights of the person with dementia
- Recognition of the need for comprehensive services from diagnosis to end-of-life to address the needs of all people with dementia, including younger people (early-onset) and those with Down Syndrome and Alzheimer’s Disease
- Bias towards home care solutions with strong support for families and local communities
- Access to services determined solely on the basis of need rather than by income, social class or geography

## 1.4 Dementia: globally and in Ireland

There are about 35 million people around the world today with dementia, about 9 million of whom live in Europe. Countries across Europe whose populations are significantly older than Ireland’s such as Germany, France, the UK, the Netherlands, Switzerland, Italy and the Scandinavian countries have obviously much larger proportions of people now living with dementia. Compared with Ireland, several of these countries are considerably more advanced in relation to their development of policy on dementia and, more specifically, the development of respective national action plans for dementia. France, England, Scotland, Northern Ireland, the Netherlands, Norway and Australia, for example, could today be considered world leaders in developing dementia policy and, accordingly, lessons can be learned from their experiences by countries such as Ireland who are not nearly as well advanced in the development of health and social policy on dementia.

Dementia remains a hugely neglected, underfunded and under-prioritised health issue in Ireland. This is at a time when across Europe considerable progress has recently been made in mobilising joint action in the fight against Alzheimer's disease and the related dementias and in the development of a European Initiative on Dementia (European Commission, 2009). For example, since 2006 when Nicolas Sarkozy first announced the Paris Declaration on Dementia, neurodegenerative diseases, particularly Alzheimer's disease, has been singled out as a domain of huge importance at a European level and European Union (EU) member states have been urged to develop National Action Plans on dementia and work collaboratively at European and international level in the fight against dementia. The development of a National Strategy for Dementia in Ireland is, therefore, overdue and will play an important role in mobilising public support and public resources for action on dementia.

## 1.5 Background to this dementia review

Against this backdrop (including a European Initiative on Alzheimer's Disease and the related dementias launched in 2009) and following years of political advocacy, the politicisation of dementia and repeated calls for the development of an Irish Dementia Strategy, in April 2010 the then Minister for Health Promotion and Older Persons publicly announced the Irish Government's commitment to establishing a National Dementia Strategy. A few months later a meeting was organised by The Atlantic Philanthropies (AP) of their major grant-holders and representatives of the Department of Health to explore common ground in relation to making progress on the development of a new Strategy. The round-table discussion involving key AP stakeholders resulted in a decision being reached that a major research review on dementia was a necessary and priority requirement for the development of a comprehensive Strategy. Although *An Action Plan on Dementia*, published in 1999, was an extremely valuable policy document at the time of publication, as was a review of policy for dementia care undertaken by O'Shea (2007), there was a need for a major updated review to reflect developments in relation to dementia care, prevalence and current economic and social conditions.

The new review was considered critical for the design of an effective and responsive National Dementia Strategy. A coalition of interests in dementia care was considered imperative in order to advocate for the prioritisation of dementia in public resource allocation processes (Cahill, 2010). It was noted that national dementia strategies developed in other countries, including England, Northern Ireland, Scotland, Norway, Australia and Canada, were underpinned by substantial evidence-based research. In addition, experience from other countries indicated that commitment from government was a key to the successful development of a National Dementia Strategy (Burns, 2010). It was also recognised that while the creation of a research evidence base was a necessary condition for the development of a new Strategy, it was not a sufficient condition. The latter required the direct involvement of the Department of Health and a much wider coalition of interests and stakeholders than needed to be included in the construction of the preliminary research evidence base.

As mentioned above, a public commitment to an Irish Dementia Strategy had already been given in 2010 and this was reiterated by the new Coalition government when in its Programme for Government for 2011-2016 it was stated:

We will develop a national Alzheimer's and other dementias strategy by 2013 to increase awareness, ensure early diagnosis and intervention, and development of enhanced community based services. This strategy will be implemented over five years (p. 38).

The purpose of this chapter is to explain how the research review required to inform the government in its development of this future Strategy was undertaken, the content of the review including the broad parameters covered, how and by whom the review process was governed and how the areas chosen broadly link in with European policy on dementia. The chapter also provides information on how the literature review undertaken has helped shape the way in which dementia is conceptualised in this report. The chapter concludes with a synopsis of what is contained in the seven chapters to follow.

## 1.6 Creating the evidence-based research

In October 2010, some six months after the government's public announcement of its commitment to develop an Irish Dementia Strategy, philanthropic funding was granted to researchers from the Living with Dementia research programme (LiD) in Trinity College Dublin (TCD) and the Irish Centre for Social Gerontology (ICSG) in the National University of Ireland, Galway (NUIG) to undertake the evidence-based dementia research review necessary to lay the foundations for the new National Dementia Strategy for Ireland. At the outset it was agreed that no new major research studies would be undertaken, but rather the review would entail an extensive literature search, the collation of information (including that derived from meetings with key informants) and the analysis of secondary datasets in order to generate new state of the art information about dementia care and dementia services for Ireland.

## 1.7 Review objectives

The objectives of this evidence-based research review, as agreed between the funders (AP), the Department of Health and the contract researchers, were fourfold:

1. to review current and future demographic trends in Ireland and provide estimates of current and future dementia prevalence rates, in relation to both those aged 65 and over and younger people;
2. to specify the main economic costs of dementia care;
3. to review current service availability (based on the recent HSE audit) and estimated future demand for services;
4. to review best practice in dementia care locally and internationally.

The topics identified for this review were timely and broadly speaking fit well with the European Initiative on Alzheimer's disease and the related dementias (European Commission, 2009), the objectives of which are:

- (i) Early action to diagnose dementia and promote well-being (1 & 3)
- (ii) A shared European effort to better understand dementia conditions - improving epidemiological knowledge and co-ordination of research (1)
- (iii) Supporting national solidarity with regard to dementia, sharing best practices for the care of people with dementia (4) and
- (iv) Respecting the rights of people with dementia (3 & 4)

In awarding the start-up grant, AP, supported by the Department of Health, considered it critical that a multi-disciplinary Dementia Advisory Committee be established to guide and oversee the evidence-based research review. While the Advisory Committee included key stakeholders, it was not intended to be representative of all agencies and organisations involved in dementia care. The function was to guide the research process only (see Appendix A for the terms of reference and membership of the Dementia Advisory Committee). The Committee was jointly chaired by Associate Professor Suzanne Cahill and Professor Eamon O'Shea and met in total eleven times during the course of the project. The evidence-based research review officially commenced in January 2011 with the appointment of Dr Maria Pierce as Research Fellow to the project. The review was completed in December 2011.

## 1.8 Methodology

The review was based on an extensive literature search of national and international books, reports, website, newspaper coverage and journal articles, using the following search engines CINAHL, PsychInfo, PubMed and Social Sciences Index and keying relevant words and word combinations including dementia prevalence, cost of care, dementia strategy, primary care, community care, residential care, policy, end of life, early onset, dementia, training, Down syndrome and dementia, Alzheimer's disease. The review was also based on secondary analysis of any Irish

database, register or statistical report deemed relevant in the generation of this new state of the art information, particularly in relation to prevalence, costs and services. In the section to follow, approaches used to generate information for the four key actions entailed in the review are detailed.

## 1.8.1 Prevalence and projections of dementia

Using data from the Census of Population 2006, new estimates of the prevalence of dementia in Ireland were generated. First, calculations were undertaken to estimate the number of men and women in each of the following nine age groups (30-59, 60-64, 65-69, 70-74, 75-79, 80-84, 85-89, 90-94 and 95+). Next, EuroCoDe<sup>1</sup> age/gender-specific dementia prevalence rates were applied to each gender disaggregated age group, starting with the age groups 60-64. As EuroCoDe does not specify prevalence rates for the age category 30-59, the relevant EURODEM<sup>2</sup> prevalence rates were applied instead.

To generate new estimates of the prevalence of dementia at a local level, numbers of people in the same nine age groups were calculated for each of the Health Service Executive's 32 Local Health Office (LHO) areas. EuroCoDe age/gender specific prevalence rates were then applied to generate the prevalence of dementia in the population of each of the 32 LHO areas.

With a view to estimating the prevalence of dementia in different community, nursing home and hospital care settings, the available Irish and international published literature on prevalence of dementia in each of these settings was reviewed for this report. Data from the Census of Population 2006 was used to arrive at estimates of the prevalence of dementia in the community. Official data from the Department of Health's Long Stay Activity Statistics and data collected via the Hospital In-Patient Enquiry (HIPE) were reviewed to ascertain if and how they could be used in calculating prevalence of dementia in nursing home and hospital settings.

Two sets of estimates of the future numbers of people with dementia in Ireland for the period 2011 to 2041 were generated. These relied on the most recently available population projections for Ireland from the Central Statistics Office (CSO, 2008a), which provides population projections at five year intervals between 2011 and 2041 for six combinations of fertility and migration assumptions (i.e. M1F1, M1F2, M2F1, M2F2, M0F1 and M0F2). From these, age- and gender-disaggregated projections based on M0F2 and M2F1 assumptions were selected and used as a basis for calculating the two sets of predictions of the future numbers of people with dementia for this study. Estimates of the projected numbers of people with dementia by age group in Ireland at five yearly intervals from 2011 to 2041 were generated by applying the EuroCoDe age/gender-specific prevalence rates of dementia to these two sets of projections. Chapter 2 explains in detail the way in which these population projections were calculated and discusses the limitations associated with making such projections.

## 1.8.2 Economic and social costs of dementia

Cost of illness studies offer a useful way to document the origins and extent of care costs in relation to particular diseases. They require the identification, measurement and valuation of all resources related to a particular disease. The output, expressed in monetary terms, is an estimate of the total cost of a particular illness to society (Rice, 1994). While cost of illness studies are not without their critics, both in terms of their methodology (Drummond, 1992) and their usefulness (Byford, Torgerson and Raftery, 2000), they are very valuable in determining not only the cost of an illness but also the distribution of costs across budgets and sectors of the community. Chapter 3 provides an estimate of the economic and social costs of dementia in Ireland for 2010, drawing on an eclectic range of sources to estimate resource use and unit costs. One of the difficulties of undertaking this type of research for Ireland is the

<sup>1</sup> European Collaboration on Dementia.

<sup>2</sup> The European Community Concerted Action on the Epidemiology and Prevention of Dementia Group

weakness of the information base, particularly the absence of consistent data on utilisation and unit costs, either generic or dementia-specific. Nevertheless, considerable progress is made in this report in estimating detailed and comprehensive costs for dementia that show the absolute and relative cost of the disease in Ireland.

### 1.8.3 Current availability and future demand for services

A scoping exercise collating information on all known and published health and social services available to people with dementia in Ireland was initially undertaken through an analysis of a wide range of relevant official databases and registers such as HSE databases including: (i) the Day Care Survey 2009 (ii) the National Register on public and voluntary nursing homes bed; (iii) the home care services database; and (iv) the Old Age Psychiatry database, HIQA's register of nursing homes and statistical reports (e.g. Department of Health's Long-Stay Activity Report). Certain non-governmental databases (e.g. Alzheimer's Society of Ireland (ASI) database on service utilisation) and statistical reports (e.g. Nursing Homes Ireland (NHI) annual survey) were also consulted. A full list is presented in Appendix C. Interviews with key people in the Department of Health, the HSE, the ASI and other service provider organisations were also undertaken to source relevant information on dementia services. This was followed by a mapping exercise of the key health and social care services known to be available to people with dementia in Ireland. The mapping exercise proved very difficult as available data on general or dementia-specific service provision at national and local level was patchy and extremely limited. While more data is now becoming available on older peoples' services, there is a distinct paucity of data available on dementia-specific services and the absence of useful and timely data remains a key constraint to priority-setting in this area. Nevertheless, using the available data, the study collated information on service provision across a range of care settings, including primary, community, day care, residential and hospital.

### 1.8.4 Best practice in dementia care locally and internationally

A review of National Dementia Plans/Strategies from seven European countries, namely, England,<sup>3</sup> Northern Ireland,<sup>4</sup> Scotland,<sup>5</sup> Wales,<sup>6</sup> France,<sup>7</sup> the Netherlands<sup>8</sup> and Norway<sup>9</sup> was undertaken. Strategies were systematically analysed and reviewed in the context of their relevance to Ireland and to our evolving Dementia Strategy. Questions posed included: What principles and key concepts underpin these European Strategies? What areas are prioritised and why? How does research evidence inform these Dementia Strategies? What is the overall approach including implementation plan used in these Strategies? Other questions posed included; What models of service reform are being recommended in these National Strategies? What models of best practice are in evidence and what lessons can be learned by Ireland from other countries' experiences? In addition to these European National Dementia Strategies and Plans, the Australian National Framework for Action on Dementia 2006-2010 (AHMC, 2006) and the Rising Tide report, the Alzheimer Society of Canada's call for action on a Canadian-wide National Dementia Strategy (ASC, 2010) were also reviewed. International experts on dementia were also consulted including Professor Sube Banerjee and Professor Julian Hughes.

<sup>3</sup> Department of Health (2009).

<sup>4</sup> DHSSPS (2011).

<sup>5</sup> Scottish Government (2010).

<sup>6</sup> Welsh Assembly Government and Alzheimer's Society (2011).

<sup>7</sup> Government of France (2008).

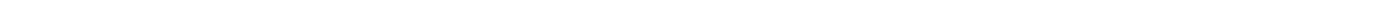
<sup>8</sup> Ministry of Health, Welfare and Sports (2004).

<sup>9</sup> Norwegian Ministry of Health and Care Services (2007).



## 1.9 Report structure

The structure of this report, broadly speaking, follows the key objectives of the research review as detailed on page 11. Chapter 2 reports on the prevalence of dementia globally and in Europe. It then proceeds to present new data on current and future estimates of dementia prevalence rates for Ireland up until 2041. This chapter also provides new information on the prevalence of dementia across each of the 32 LHO areas and discusses the difficulties involved in estimating dementia prevalence for patients in hospitals and residents in long-term care. Chapter 3 provides new up-to-date information on the cost of dementia care in Ireland. Factoring in all possible direct and indirect, formal and informal costs of care, the total cost of dementia care in Ireland in 2010 is estimated and compared to costs internationally and across other diseases. The idea of a notional journey through dementia is used as a framework to identify and summarise research evidence on current service availability and future demand for services in Chapters 4 to 7. Chapters 4 and 5 review diagnostic and post-diagnostic services, primary, secondary, community care services, and psychosocial supports available to community-dwelling people with dementia in Ireland. Chapter 6 discusses hospital services and Chapter 7 discusses residential care services for people with dementia. Running through all chapters are the lessons learned from a perusal of the action plans and strategies of other countries, particularly in relation to diagnosis, pathways to care, resource allocation and priority-setting.





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# CHAPTER 2

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## PREVALENCE AND PROJECTIONS OF DEMENTIA

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“

If we could just delay the onset by two years, that would reduce the prevalence by 20%. If we could delay it by five years, it would halve the prevalence (*Brodsky, 2008: 11*)

”

# CHAPTER 2

## Prevalence and projections of dementia

### 2.1 Introduction

The risk of developing dementia increases exponentially with age and global ageing means that in the next few decades very large numbers of people around the world will enter the age where the incidence of dementia will be highest. Accordingly, and in the future, unless a cure is found, dementia is set to become a worldwide epidemic and Ireland will be no exception to this phenomenon. The population of older people (those aged 65 and over) in Ireland who currently represent 11% of our total population, is expected to double from approximately 0.5 million today to over 1 million by 2031. With this rapid increase in the number of older Irish people, treatment and care provision for those with chronic diseases of ageing, especially Alzheimer's disease and the related dementias, will take on increasing importance. In this context, accurate national estimates of current and future prevalence of dementia will be essential for effective planning of health and social care services and for generating awareness about this costly disease. There is an urgent need to collate facts and figures to build an evidence base in order to develop adequate health and social policy responses, hence, the timeliness of this report.

It has been noted that the ideal way to arrive at reliable dementia prevalence estimates is to conduct national representative surveys based on population or regional samples. However, these approaches are extremely costly and require large teams of carefully trained researchers. For the purposes of this report, therefore, and in line with approaches used in other European studies, dementia prevalence estimates have been calculated for Ireland based on EURODEM and EuroCoDe age/gender-specific prevalence formulae.

This chapter commences with a discussion of global and European dementia prevalence estimates with reference to age/gender prevalence rates generated by EURODEM and EuroCoDe. Sections 2.4 to 2.6 presents recent Irish data on dementia prevalence based on the Irish 2006 Census data and the National Disability Survey 2006. This is followed by section 2.7, which applies EuroCoDe prevalence rates to the same Census data to estimate prevalence rates at local (LHO) level. Sections 2.8 and 2.9 review the only official statistics available on people with dementia in nursing homes and acute hospital care, respectively. Comparisons in this section are made with national and international data. Section 2.10 applies the EuroCoDe dementia age/gender-specific prevalence rates to the CSO (2008) population projections to arrive at estimates of the number of people with dementia in Ireland by age group between 2011 and 2041. The limitations associated with such projections are outlined in Section 2.11. Section 2.12 reviews data from TILDA and Section 2.13 provides a brief discussion of the incidence of dementia in Ireland. The chapter concludes by providing a summary of the key findings emerging from this review.

### 2.2 Estimating the prevalence of dementia in Europe

Since the 1990s, several European studies based on probability (representative) samples have been conducted to estimate dementia prevalence rates at a national level (Berr et al., 2005). Findings from these studies show that prevalence rates vary widely both between studies undertaken in different countries and even within countries (Berr et al., 2005; van der Flier and Scheltens, 2005). A different approach taken is to combine data from multiple studies in what is known as meta-analysis. The latter, according to van der Flier and Scheltens (2005), is particularly advantageous, since (1) small differences arising from methodological differences between countries are levelled out; and (2) the analysis is based on a much larger sample than a single study could ever realise.

In the context of dementia prevalence estimates, the meta-analysis approach was first adopted by the European Studies of Dementia network known as EURODEM in 1991. Results on dementia prevalence rates in Europe based on a collaborative eight country epidemiological study were then published (Hofman et al., 1991). This work was updated in 2000 (Lobo et al., 2000) when findings showed that approximately 3.3 million

people aged 65 years and over and living in the EU had dementia. The EURODEM meta-analyses has, for some time, been considered the best reference for dementia prevalence rates for Europe (Berr et al., 2005).

More recently, EuroCoDe<sup>10</sup> has undertaken a meta-analysis based on 26 European studies and age/gender-specific prevalence rates have been calculated (Reynish et al., 2009). Interestingly, this analysis has confirmed the existing prevalence rates of dementia for men in all age groups and for women in age groups up to the age of 85 years. However, the review found that for women over 85 years, prevalence estimates were higher than was previously reported. Reynish et al. (2009: 3) concluded that ‘epidemiological studies of dementia prevalence in Europe continue to show constant rates in all age ranges with the female oldest old being the exception’. Based on EuroCoDe project methodology, the European Commission has since 2009 been fully committed to producing reliable prevalence and incidence data on dementia according to age, and under the Health Programme has committed to develop actions for improving dementia prevalence data at a European level.

**Table 2.1:** EURODEM and EuroCoDe age/gender-specific prevalence rates of dementia

Age Range	EURODEM (1991)			EuroCoDe (2009)	
	Men	Women	Both Sexes	Men	Women
30-59	0.2%	0.1%	0.1		
60-64	1.6%	0.5%	1.0	0.2%	0.9%
65-69	2.2%	1.1%	1.4	1.8%	1.4%
70-74	4.6%	3.9%	4.1	3.2%	3.8%
75-79	5.0%	6.7%	5.7	7.0%	7.6%
80-84	12.1%	13.5%	13.0	14.5%	16.4%
85-89	18.5%	22.8%	21.6	20.9%	28.5%
90+ <sup>1</sup>	31.9%	34.1%	–	–	–
90-94	32.1%	32.3%	32.2	29.2%	44.4%
>95	31.6%	36.0%	34.7	32.4%	48.8%

**Source:** EURODEM age/gender-specific prevalence rates of dementia: Hofman et al. (1991), Tables 4, 5 and 6, pp. 742-44; EuroCoDe age/gender-specific prevalence rates of dementia: Alzheimer’s Europe (2009).

Notes: <sup>1</sup> as used by O’Shea, 2007: 7, Table 1.

The EURODEM (1991) and the EuroCoDe (2009) age and gender-related dementia prevalence rates are shown in Table 2.1. The table shows much consistency in trends on prevalence data stratified by age and gender using both methods of calculation. One exception noted, however, is in the estimated prevalence rates for women aged 85 and over using the EuroCoDe estimates, where an increase in the prevalence of dementia is evident.

<sup>10</sup> EuroCoDe was funded in 2005 by the European Commission under the Community Public Health Programme for neuro-degenerative disease.

## 2.3 Global estimates of dementia prevalence

Around the same time as efforts were taking place at a European level to estimate dementia prevalence rates, in 2004, Alzheimer's Disease International (ADI) convened an international group of experts and using the Delphi consensus method,<sup>11</sup> generated evidence-based age-specific global dementia prevalence rates. The group calculated that, for the year 2001, there were 24.2 million people aged 60 years and over with dementia worldwide (Ferri et al., 2005). One shortcoming of the approach adopted by this international group was the fact that gender-specific estimates were not calculated. A strength, however, was that these experts brought their analysis forward by estimating the numbers of people likely to be affected by dementia globally and in each of the world regions by the years 2020 and 2040. Based on United Nations (UN) population projections, they estimated that worldwide dementia prevalence rates would double every 20 years to 42 million by 2020 and 81 million by 2040. Their estimates were calculated in five year bands from 60 to 85 and for those aged 85 years and over. They also provided standardised prevalence rates for those aged 60 and over for each region (Ferri et al., 2005). Table 2.2 shows the age-specific prevalence rates of dementia and standardised prevalence for those aged 60 years and over for the EURO A region, that is, Western Europe.

Later, in 2009, two of the lead authors from this highly regarded international epidemiological study (Ferri et al., 2005) generated age/gender-specific estimates of the prevalence of dementia for each region of the world (Prince, 2009). The study estimated that worldwide and at the time of writing, 35.6 million people over 60 years would be living with dementia in 2010 and that worldwide these numbers would double every 20 years to 65.7 million by 2030 and to 115.4 million by 2050. These revised estimates are approximately 10% higher than those reported earlier (Ferri et al., 2005).

Both Ferri et al. (2005) and Prince (2009) agree that Western Europe, compared with other parts of the world, has the highest number of people with dementia (Ferri et al., 2005; Prince, 2009). Whilst Ferri et al. (2005) estimated that 4.9 million people were living with dementia in Western Europe and forecast that this figure would rise to 9.9 million by 2040, Prince's estimates (2009) were less conservative and estimated that for 2010 there were approximately 7 million Western Europeans with dementia and forecast that these numbers would increase to 10 million in 2030 and to 13.4 million in 2050.

**Table 2.2:** Age/gender-specific prevalence rates of dementia and standardised prevalence rate for those aged 60 years and over for the Western Europe region

Age range	EURO A (Ferri et al., 2005)	Western Europe (Prince, 2009)		
		Both sexes	Men	Women
60-64	0.9%	1.4%	1.9%	1.6%
65-69	1.5%	2.3%	3.0%	2.6%
70-74	3.6%	3.7%	5.0%	4.3%
75-79	6.0%	6.3%	8.6%	7.4%
80-84	12.2%	10.6%	14.8%	12.9%
85+	24.8%			
85-89		17.4%	24.7%	21.7%
90+		33.4%	48.3%	43.1%
Standardised prevalence for those aged 60 years or over	5.4%			6.92%

Source: Ferri et al. (2005), Tables 1 and 2, pp. 2114-5; Prince (2009) Table 1.5, p. 36.

<sup>11</sup> Delphi Consensus Method is a systematic review of all relevant studies and the evidence is synthesised into a single consensus estimate of likely prevalence by a group of experts.

## 2.4 Estimates of the prevalence of dementia in the population of Ireland

One of the earliest Irish attempts to estimate the prevalence of mental illnesses and mental disorders including dementia in a regional community-based sample was undertaken in the Dublin area in the mid 1990s. The researchers in this study, using AGE-CAT (Automated Geriatric Examination for Computer Assisted Taxonomy), estimated dementia prevalence rates for people aged 65 years and over of between 4.1% (Kirby et al., 1997) and 5.5% (Lawlor et al., 1994), which is consistent with the findings of similar studies in Liverpool and New York (Copeland et al., 1987a, 1987b).

As stated earlier, undertaking population-based epidemiological studies to estimate the prevalence of any disease, including dementia, is time-consuming, complex and costly. Ireland continues to lack reliable epidemiological data on dementia prevalence. However, like other European countries, in the absence of good and reliable national epidemiological data, researchers in Ireland have applied both the EURODEM and EuroCoDe age/gender-related dementia prevalence to Irish population data to estimate the number of people likely to have dementia in the country.

Using the EURODEM calculations, estimates based on the 2002 Census data suggested that in that same year there were approximately 34,286 people with dementia in Ireland (O'Shea, 2007). Based on the 2006 Census, these figures were later revised to approximately 37,900 (Diaz-Ponce, 2008). Table 2.3 reports Census data for 2002 and 2006 and related dementia prevalence estimates for the same years using the EURODEM approach for calculation.

**Table 2.3:** Estimated Number of People with Dementia in Ireland from 2002 and 2006 Census as per EURODEM prevalence rates (Reproduced from Diaz-Ponce, 2008: Table 2)

Age Category	Male Census 2002	Females Census 2002	Male Census 2006	Females Census 2006	Males with dementia 2002	Females with dementia 2002	Persons with dementia 2002	Male with dementia 2006	Females with dementia 2006	Persons with dementia 2006
30-59	773421	771706	869212	850724	1547	772	2319	1738	851	2589
60-64	77559	76693	91561	90166	1241	383	1624	1465	451	1916
65-69	651719	68184	70895	72501	1436	750	2186	1560	798	2357
70-74	51719	60410	56540	62612	2379	2356	4735	2601	2442	5043
75-79	37377	52438	40121	52345	1869	3513	5382	2006	3507	5513
80-84	22283	36574	24694	40190	2696	4937	7633	2988	5426	8414
85-89	9444	20185	11021	22281	1747	4602	6349	2039	5080	7119
90+	3042	9055	3824	10902	970	3088	4058	1216	3718	4934
<b>Total</b>					<b>13,885</b>	<b>20,401</b>	<b>34,286</b>	<b>15,613</b>	<b>22,271</b>	<b>37,884</b>

**Source:** Census of Population, 2002, by EURODEM prevalence rates as calculated by O'Shea (2007); Census of Population, 2006, by EURODEM prevalence rates as calculated by Diaz-Ponce (2008).

Interestingly, and in keeping with most other European countries, the table shows a consistent gender bias in dementia prevalence for age groups 75 years and over with women having higher prevalence rates, mainly due to the disproportionate number of women in the population at older ages. In the age category less than 75, this gender bias is reversed with dementia prevalence rates identified as being higher in males compared with females.

**Table 2.4:** Estimated number of people with dementia by age groups and gender in Ireland, 2006, as per EURODEM and EuroCoDe age-related dementia prevalence rates (n)

Age range	Total Population (Census 2006)†		Persons with dementia (estimated using EURODEM (1991) ageing-related dementia prevalence rate)‡			Persons with dementia (estimated using EuroCoDe (2009) age/gender-related dementia prevalence rates) ∞		
	Men	Women	Men	Women	Total	Men	Women	Total
30-59	869,212	850,724	1,738	851	2,589	1,738 <sup>1</sup>	851 <sup>1</sup>	2,589
60-64	91,561	90,166	1,465	451	1,916	183	811	994
65-69	70,895	72,501	1,560	798	2,357	1,276	1,015	2,291
70-74	56,540	62,612	2,601	2,442	5,043	1,809	2,379	4,188
75-79	40,121	52,345	2,006	3,507	5,513	2,808	3,978	6,786
80-84	24,694	40,190	2,988	5,426	8,414	3,581	6,591	10,172
85-89	11,021	22,281	2,039	5,080	7,119	2,303	6,350	8,653
90+	3,824	10,902	1,216	3,718	4,934			
90-94	3,231	8,814				943	3,913	4,856
95+	593	2,088				192	1,019	1,211
<b>Total</b>			<b>15,613</b>	<b>22,271</b>	<b>37,884</b>	<b>14,833</b>	<b>26,907</b>	<b>41,740</b>

Source: †CSO (2007a) Census of Population - Volume 2: Age and Marital Status, Tables 2B and 2C, pp. 16-17 and Table 5, p. 28; ‡Diaz-Ponce (2008), Table 2; ∞New prevalence figures generated by applying EuroCoDe age-related prevalence rates applied to Census 2006 data.

Notes: <sup>1</sup> As EuroCoDe does not specify young onset prevalence rates, EURODEM young onset dementia prevalence rates were used instead.

More recently, and for the purpose of this research review, EuroCoDe age/gender specific dementia prevalence estimates have been applied to the 2006 Census of Population.<sup>12</sup> Accordingly, estimates based on the 2006 Census (that is, 37,884) have now been revised upwards to 41,740 for the same year. This data is reported in Table 2.4.

## 2.5 Younger people with dementia in Ireland

It is recognised that younger people with dementia (those aged less than 65) are a particularly vulnerable group whose needs and experiences are far more complex than those of older people with cognitive impairments (Haase, 2005). Yet, currently there is an absence of reliable epidemiological data reporting on the prevalence of early onset dementia in Ireland. This type of information is urgently needed in order to plan future service provision and in order to estimate future health and social care costs. Applying the EuroCoDe prevalence rates to the 2006 Census data for Ireland suggests that 3,583 of the estimated 41,740 (approximately 8.6% of all people with dementia) had early onset dementia and most of these were young men (see Table 2.4).

Counting cases of young-onset dementia that come to medical attention is a more reliable method of estimating the numbers of younger people with dementia than population or community studies (Henderson and Jorm, 1998). New information on the number of younger people with Alzheimer's disease in the Greater Dublin Area will in the future be generated by a population-based study of Young-Onset Neurodegeneration illnesses (YON) being conducted by a

<sup>12</sup> Whilst early results from the Census of Population 2011 (CSO, 2011a) were available at the time of writing of this report, more detailed breakdowns (by age and gender) needed to generate prevalence of dementia rates will not be available until 2012.



research group in Neurodegeneration within the Dublin Centre for Clinical Research.<sup>13</sup> The aim of this study is to collect information and establish a database of all young patients (aged 40 to 64) who have a primary neurodegenerative condition, including Alzheimer's disease and related conditions, and who live in the Greater Dublin area.

## 2.6 Prevalence of dementia in people with Down Syndrome

The Irish dementia prevalence rates may be slightly underestimated as they exclude data on people with intellectual disability (ID) including those with Down syndrome and dementia. People with an ID in general but not Down syndrome have no excess risk of developing a dementia. However, those with Down syndrome are at a heightened risk and there is a large body of research evidence which provides convincing evidence that rates of Alzheimer's type dementia are significantly higher in persons with Down syndrome compared with that of the general population (Prasher and Krishnan, 1993). Age-related disorders including dementia begin earlier in people with Down syndrome than in the general population (Bittles and Glasson, 2004). Whereas dementia normally begins to present in a healthy population after the age of 65 it is said to occur amongst people with Down syndrome at a mean age of 54.7 years (Tyrell et al., 2001). Unfortunately, all people with Down syndrome will eventually develop Alzheimer's type dementia if they live long enough.

It is because this group of people are at such heightened risk of developing early-onset Alzheimer's type dementia that reliable and valid data on the numbers of people in Ireland with Down syndrome is urgently needed. Because the life expectancy of people with Down syndrome has increased so dramatically in recent years,<sup>14</sup> it is likely that the number with dementia has also increased. One of the key issues that will be elaborated upon in later chapters is that services for people with dementia at younger ages are poorly developed, even in comparison to services for older people with dementia. At least at older ages, systems and structures exist that recognise dementia, but that is not the case for younger people, who, as a consequence, may have to share services and facilities that are not age appropriate, assuming that they exist at all. Moreover, it is more difficult to diagnose dementia in people with Down syndrome due to communication difficulties and other barriers associated with conducting the normal battery of memory and cognitive assessment.

The Census does not provide information about people with Down syndrome in Ireland, although useful information is available from the Census on numbers of people in Ireland with ID (58,865) of whom less than 7% are aged 65 years and over. A National Intellectual Disability Database (NIDD) is also being maintained by the Health Research Board (HRB) in Ireland. However, the database, although providing information on disability, levels of severity and age, fails to generate information on disability type and, therefore, provides no information on people with Down syndrome.

<sup>13</sup> This is a collaborative initiative between three universities across Dublin (Royal College of Surgeons, Trinity College Dublin and University College Dublin) to support specialists across Dublin to carry out research studies. It is also being carried out in four hospitals across Dublin (Beaumont Hospital, St. Vincent's University Hospital, the Mater Misericordiae University Hospital and St. James's Hospital).

<sup>14</sup> For example, over 80 years ago (1929) life expectancy for people with Down syndrome was 25 years. By 1997 life expectancy for people with Down syndrome had increased to 49 years (Baird and Sadovnick 1988; Yang et al. 2002). Bittles and Glasson (2004: 283) suggest that the 'within the next generation, people with Down syndrome will be living as long as the general population'.

Efforts to narrow the gap in our knowledge about the number of people with Down syndrome in Ireland came about in 2008 when the National Disability Survey (NDS) report was published. This report showed that there were approximately 5,500 people with Down syndrome in Ireland (CSO, 2008c). On the basis of this figure, and given we know that in Ireland, in line with other countries (Prascher and Krishnan, 1993; Devenny et al., 1996; Zigman et al., 1995), the overall prevalence of dementia among people with Down syndrome is around 13.3% (Tyrrell et al., 2001), we can deduce that there are approximately 700 people in Ireland with Down syndrome and dementia.

More specific age-related prevalence figures for dementia among people with Down syndrome have been calculated in Ireland (Tyrrell et al., 2001) and are presented in Table 2.5. While it is not possible to apply the age-related prevalence rates as data from the NDS 2006 is not disaggregated by age, it is evident from research that there is an age-related increase in dementia in people with Down syndrome.

**Table 2.5:** Age-related prevalence of dementia among people with Down syndrome

Age	Prevalence rate
<40	1.4%
40 to 49	5.7%
50 to 59	30.4%
60 to 69	41.7%
>70	50.0%

Source: Tyrrell et al, 2001, Table 1, p. 1170.

## 2.7 New prevalence of dementia data at regional and local level in Ireland

The Census 2006 provides data on the population of Irish men and women stratified by age and located in each of the HSE 32 LHO areas. It also provides data on the same population living in each of the 26 counties of the Republic of Ireland. For this report, based on this Census data and applying the EuroCoDe age/gender specific dementia prevalence rates, new prevalence data has been generated stratified by locale. Table 2.6 presents these findings.

The table shows some clear regional variation in estimated dementia prevalence rates across Ireland, with the West having the highest number of people with dementia (11,429) and the Dublin North Eastern region conversely having the lowest numbers at a little over 8,000. Estimates for the South of Ireland and Dublin Mid-Leinster are similar at 11,273 and 10,924 respectively. The table shows that LHO areas in the HSE West region have the highest prevalence rates of dementia with each of the nine areas estimated to have at least 1% of its total population living with dementia.

These new findings are in accordance with earlier estimates of dementia prevalence rates produced in Ireland, based on the 2002 Census, which also identified the West of Ireland as having the highest dementia prevalence (O'Shea, 2007). This regional variation in dementia prevalence arises as a direct result of differences in age structure across LHO areas and needs to be carefully considered by service planners and policymakers.

**Table 2.6:** Estimated number and percentage of persons with dementia in Ireland (2006) by HSE Local Health Office (LHO) area, as per EuroCoDe dementia prevalence rates (n)

HSE Region	HSE LHO area	Population (all ages)	Persons with dementia	% of total LHO population
South	Carlow/Kilkenny	120,631	1,196	0.99%
	Cork-North Lee	167,701	1,448	0.86%
	Cork-South Lee	179,260	1,681	0.94%
	Kerry	139,835	1,717	1.23%
	North Cork	80,769	961	1.19%
	South Tipperary	88,441	1,010	1.14%
	Waterford	120,017	1,233	1.03%
	West Cork	53,565	740	1.38%
	Wexford	131,747	1,287	0.98%
	Total	1,081,968	11,273	1.04%
Dublin North East	Cavan/Monaghan	120,000	1,392	1.16%
	Dublin North	222,049	1,631	0.73%
	Dublin North Central	126,572	1,427	1.13%
	Dublin North West	185,900	1,406	0.76%
	Louth	111,267	1,048	0.94%
	Meath	162,831	1,190	0.73%
	Total	928,619	8,094	0.87%
Dublin/Mid-Leinster	Dublin South City	134,344	1,220	0.91%
	Dublin South East	110,487	1,297	1.17%
	Dublin South West	148,362	1,188	0.80%
	Dublin West	133,080	841	0.63%
	Kildare/West Wicklow	203,327	1,313	0.65%
	Laois/Offaly	137,927	1,299	0.94%
	Longford/Westmeath	113,737	1,171	1.03%
	South Dublin	136,382	1,626	1.19%
	Wicklow	109,202	969	0.89%
	Total	1,216,848	10,924	0.90%
West	Clare	110,950	1,185	1.07%
	Donegal	147,264	1,694	1.15%
	Galway	231,670	2,364	1.02%
	Limerick	151,290	1,521	1.01%
	Mayo	123,839	1,692	1.36%
	North Tipperary/East			
	Limerick	98,788	996	1.01%
	Roscommon	58,768	822	1.40%
	Sligo-Leitrim/West			
	Cavan	89,844	1,155	1.29%
	Total	1,012,413	11,429	1.13%
State	Total	4,239,848	41,720	0.98%

Source: CSO (2007a) Census of Population, 2006, SAPS Interactive Table 6 and Special tabulation from CSO: Health Service Executive Areas and Local Areas [http://census.cso.ie/censusasp/saps/Pages/Select\\_Theme\\_HSE\\_Live.asp](http://census.cso.ie/censusasp/saps/Pages/Select_Theme_HSE_Live.asp) [Accessed January 2011]; CSO Special Tabulation; Persons with dementia as per EuroCoDe age-related prevalence rates.

Note: <sup>1</sup> As EuroCoDe does not specify young onset prevalence rates, EURODEM young onset dementia prevalence rates were used instead.

## 2.8 Prevalence of dementia in long-stay care settings and in the community

In Ireland, the vast majority (90%) of Irish people aged 65 years and over live at home in private households,<sup>15</sup> whilst a minority (4.6%) reside in nursing homes<sup>16</sup> (CSO, 2007b; CSO, 2007c). Gaining reliable information about the number of people in long-stay care with a dementia is fraught with difficulty given that in Ireland, as elsewhere, dementia often remains undiagnosed and, in some cases, undetected by professional care staff.

According to the most recent Long Stay Activity Statistics issued by the Department of Health (Department of Health and Children, 2009), in Ireland, the number of people living in residential care at 31 December 2008 was estimated to be 22,613. Only 26% of these people in residential care (or 28% if residents in limited stay beds are excluded) were reported as having dementia (Department of Health and Children, 2009: 23). This would suggest that numbers of people with dementia in residential care in Ireland are under 5,880, an increase from the figure of just under 5,000 or 23.5% of nursing home residents in 2004 (Department of Health and Children, 2004; O'Shea, 2007: 10). According to the official statistics, the prevalence of dementia is much higher than the average in private nursing homes and lowest in welfare homes (Table 2.7).

In researching available evidence to produce this report and reviewing the way in which Department of Health's data on Long Stay Care Activity is recorded, it is reasonable to assume that these figures significantly underestimate actual dementia prevalence rates in residential care. The reasons for stating this are several. First, for the Department's official records, dementia is defined as severe dementia with a very specific diagnosis. In the Long-Stay Activity Statistics 2008, dementia is defined as follows: 'Severe dementia means a deterioration of the brain of a person which significantly impairs the intellectual function of the person thereby affecting thought, comprehension and memory and which includes severe psychiatric or behavioural symptoms such as physical aggression' (Department of Health and Children, 2009). Secondly, the resident classification index used to collect information from long-stay units has 11 overlapping response categories, one of which is "dementia". It is highly likely that a large proportion of residents with dementia were registered under several other non-dementia classifications such as (i) respite; (ii) chronic mental health problems; (iii) convalescence; (iv) intellectual disability; (v) palliative care; and (vi) rehabilitation. Thirdly, the statistical returns may have been completed by staff without specific training in the assessment of dementia. As such, the official statistics are likely to be a gross underestimate of the numbers of people with dementia in nursing homes.

<sup>15</sup> In the Census of Population, a private household comprises either one person living alone or a group of people (not necessarily related) living at the same address with common housekeeping arrangements - that is, sharing at least one meal a day or sharing a living room or sitting room.

<sup>16</sup> In the Census of Population, a group of persons enumerated in a nursing home are referred to as a communal establishment or a non-private household.

**Table 2.7:** Proportion of people with dementia in Long Stay Activity Statistics, 2008

Type of facility	Long stay	Limited stay	All beds
HSE Extended Care Unit	21.5%	3.2%	18.8%
HSE Welfare Home	16.2%	9.1%	15.6%
Voluntary Home/Hospital	23.5%	1.4%	20.7%
Voluntary Welfare Home	7.8%	0.0%	7.4%
Private Nursing Home	32.1%	1.1%	30.8%
All Long-Stay Facilities	28.0%	2.5%	26.0%

Source: Department of Health and Children (2009), Table B7, p. 23.

More recent work undertaken by O'Shea and his colleagues (O'Shea et al., 2008) showed results consistent with these earlier findings. In their study the proportion of people with dementia was highest in private nursing homes where just over two fifths (41.2%) of patients were classified as having dementia (as shown in Table 2.8). This figure is close to that reported by NHI (2010: 32) which found that almost 38% of residents in the private nursing homes, which had responded to the annual private nursing homes survey, had been diagnosed with dementia.

**Table 2.8:** Patients/Residents with dementia by nursing home type (%)

Facility Type	% of Patients with Dementia
Private Nursing Home	41.2%
HSE Extended Care Unit	36.4%
HSE Welfare Home	34.7%
Voluntary Home/Hospital	32.5%
Voluntary Welfare Home	16.5%
All Long-Stay Facilities	32.3%

Source: O'Shea et al. (2008), Table 5.4, p. 106.

International studies suggest that the official figure of between 26% and 28% of nursing home residents likely to have dementia is a gross underestimate. In the USA and Europe, between one-half and two-thirds (50-66%) of nursing homes residents are said to have dementia (Cahill and Diaz-Ponce, 2010). Irish studies support the view that the prevalence of dementia in nursing homes is likely to be higher than the official estimates in Ireland. In a recent study Cahill and Diaz-Ponce (2010) screened a sample of residents in four nursing homes in the Dublin area to assess cognitive impairment (CI) and found that 89% of participants surveyed were cognitively impaired, of whom 42% were severely and 27% moderately impaired. However, only one third of the participants surveyed had a clinical diagnosis of dementia (Cahill and Diaz-Ponce, 2010). Whilst moderate to severe CI is not synonymous with dementia, the findings suggest that the number of people within nursing homes in Ireland with undetected dementia is likely to be high and certainly much higher than the official figures.

## 2.9 Dementia prevalence in the acute sector

Notwithstanding the difficulties (for example, dementia might not be the admitting diagnosis or hospitalisation might affect cognitive functioning) in calculating the actual prevalence of dementia in the acute general hospital setting (Nolan, 2007), estimates from the UK and the USA suggest that dementia is common among older hospitalised patients; typically older patients with dementia comprise between 20% and 25% of people in a general hospital (Department of Health, 2001; Silverstein and Maslow, 2006).

In Ireland, Hickey, Clinch and Groarke (1997) found that 19.3% of acute medical beds are occupied by patients with persistent cognitive impairment, and this would include people with dementia. This coincides with previous estimates from a former Health Board, which suggested that 18 per cent of acute medical beds are occupied by people with significant cognitive impairment (Clinch and Hickey, 1992).

As shown by Sampson et al. (2009), who found that 42% of individuals aged 70 years and over and 48% of people aged 80 years and over with an unplanned admission to an acute general hospital in England had dementia, the prevalence of dementia amongst patients in an acute hospital increases with age. Moreover, the prevalence of dementia across acute hospital wards varies widely and is dependent not only on the demographic profile of patients on the ward but also on the type of ward (Mukadam and Sampson, 2010).

The Hospital In-Patient Enquiry (HIPE), which provides information on discharges of cases of 'Dementia and other chronic disturbances of cerebral function' and on average length of in-patient stay of such cases, will be discussed in Chapter 6, as will the general topic of services for people with dementia in acute hospital settings.

## 2.10 Estimates of the future population of people with dementia in Ireland

Between the years 2006 and 2041, the Irish population is expected to increase from 4.2 million to anywhere between 4.9 million and just under 7 million depending on which assumptions are used by the CSO to model the projections (CSO, 2008a: 38-43). During the same period the number of older people aged 65 and over is expected to double. Since projections about future dementia prevalence rates in Ireland rely heavily on available population projections for Ireland, including, in particular, projections about those aged 65 and over, the next section of this chapter will explain in more detail the way in which these population projections are calculated. It will also report on new estimates of dementia prevalence up to the year 2041 based on population projections.

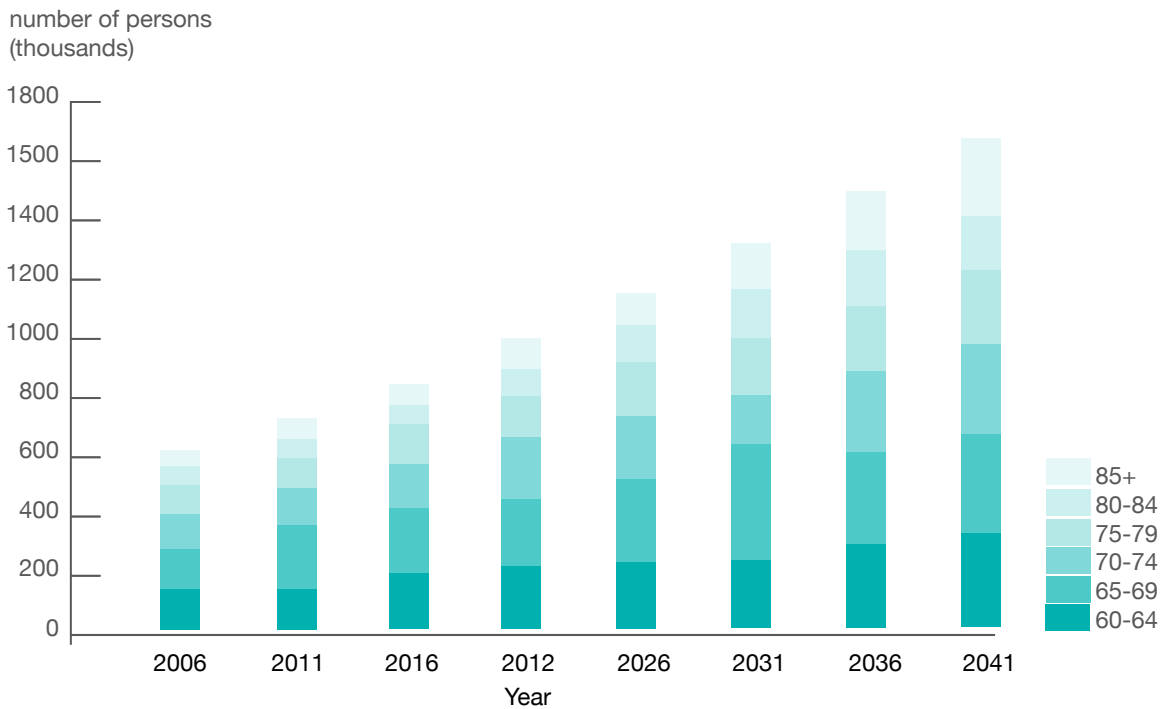
The CSO (2008a) provides population projections at five year intervals between 2011 and 2041 for six combinations of fertility and migration assumptions (i.e. M1F1, M1F2, M2F1, M2F2, M0F1 and M0F2). The projections are disaggregated by gender and five-yearly age groups. For the purpose of this review, two different sets of assumptions, namely, M0F2 and M2F1, are used to estimate population projections over the next 30 years and, accordingly, to calculate future dementia prevalence rates. These two different approaches are used since it was considered they were most relevant to current demographic (migration and fertility) trends, although margins of error are likely to be significant, even on best estimates, given the experience with previous projections.

The M0F2 projections, which forecast the lowest growth in the population, are based on the assumption that there will be zero net in-migration (M0 assumption)<sup>17</sup> and the low fertility assumption (F2 assumption), that is, the assumption that the total fertility rate will decrease over a ten-year period and then stabilise at this level until 2041. The M2F1 projections are based on the assumption that immigration will continue at moderate levels (M2); and the high fertility assumption (F1), which assumes that the total fertility rate will remain at the level observed in 2006 (1.9) for the lifetime of the projections (i.e. until 2041).

<sup>17</sup> All of the other available projections are based on either M1 or M2 assumptions, that is, it is assumed that net in-migration will continue into the future.

Chart 2.1 shows population projections based on the M0F2 assumptions. The chart shows that using this first method (M0F2) the number of people aged 65 years and over is expected to increase from 462,300 in 2006 to 885,100 in 2026 and to rise to over 1.3 million in 2041. The expected growth in the absolute number of older people over this period is at 180%. The population of the oldest old, i.e. those aged 85 years and over, is predicted to increase from 47,800 in 2006 to 248,200 people aged 85 years and over in 2041, that is, a growth of over 400% in the 35-year period (see Chart 2.1).

**Chart 2.1: Actual and Projected Population of Older People in Ireland by Age Group, 2006 - 2041 (M0F2)**

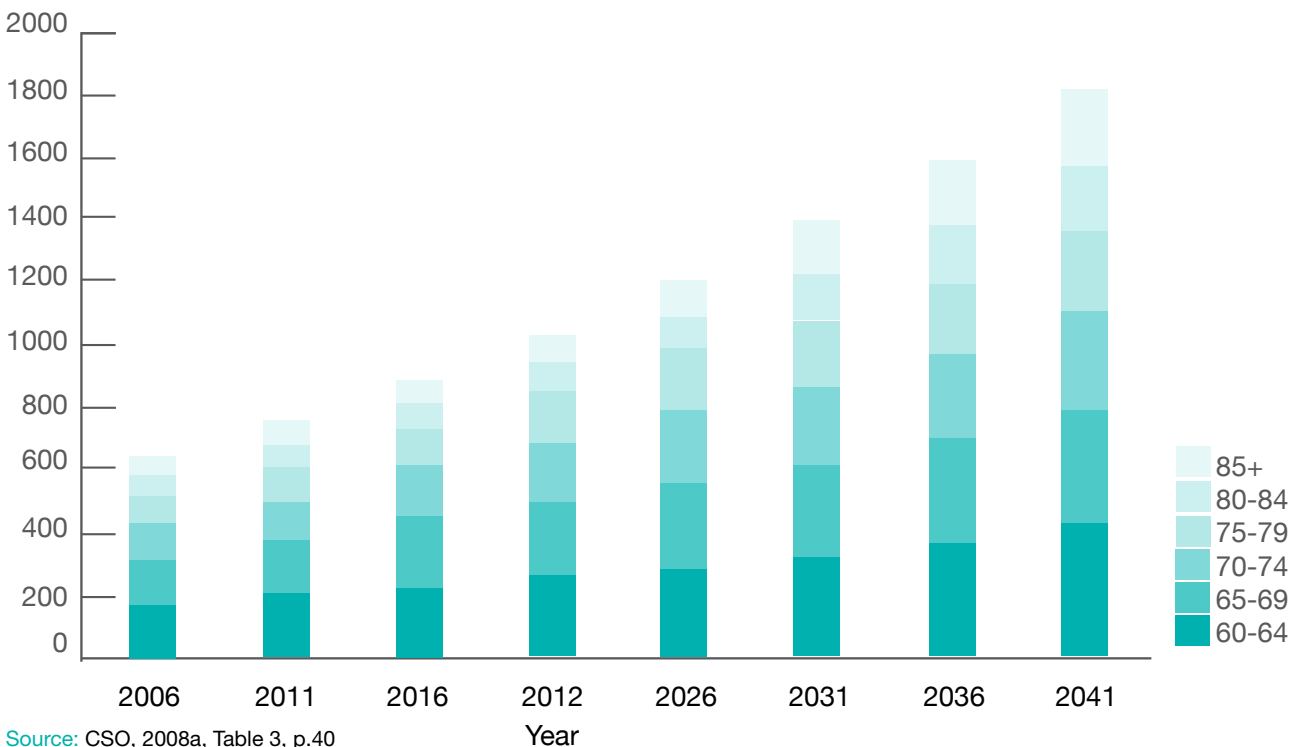


Source: CSO, 2008a, Table 6, p. 43

Chart 2.2 shows population projections up to the period 2041 using the second method, i.e. based on M2F1 assumptions. Using this approach, the population of older people is expected to increase from 462,300 in 2006 to 908,800 in 2026 and to just under 1.4 million in 2041. Thus, there is an expected growth of over 200% in older people over this 35-year period. The population of the oldest old is predicted to increase from 47,800 in 2006 to 255,100 people aged 85 years and over in 2041 (see Chart 2.2).

**Chart 2.2: Actual and Projected Population of Older People in Ireland by Age Group, 2006- 2041 (M2F1)**

number of persons  
(thousands)



Source: CSO, 2008a, Table 3, p.40

Since increasing age is the single strongest risk factor for Alzheimer’s disease and the related dementias, demographic changes characterised by a very significant increase in the numbers of older people, as reflected in these population projections, are extremely important. For the purpose of this review and applying the EuroCoDe age/gender specific prevalence rates of dementia, Tables 2.9 and 2.10 show estimates of expected prevalence rates of dementia by age group in Ireland at five yearly intervals from 2006 to 2041 using these two different sets of assumptions.

Under the MOF2 assumptions, the population of people with dementia is forecast to increase from an estimated 41,447 in 2006 to 67,493 in 2021 (a 63% increase 2006-2021) and to 140,580 in 2041 (a 240% increase 2006-2041). In line with the projected growth in the number of the oldest old population, Table 2.9 shows that the most marked increase in the number with dementia will be amongst people aged 85 years and over, with the smallest proportionate increases amongst those under 65 years of age. Under the M2F1 assumptions, the population of people with dementia is expected to increase more substantially to reach almost 70,000 by 2021 and approximately 147,000 by 2041.



**Table 2.9:** Actual number and projected growth in the number of people with dementia in Ireland by age group, 2006-2041 (M0F2) (n)

Age groups	2006	2011	2016	2021	2026	2031	2036	2041
30-59	2,576	2,803	2,967	2,982	2,930	2,869	2,791	2,686
60-64	983	1,193	1,303	1,449	1,592	1,696	1,853	2,024
65-69	2,258	2,734	3,334	3,649	4,069	4,488	4,842	5,304
70-74	4,130	4,542	5,575	6,868	7,576	8,495	9,397	10,141
75-79	6,716	7,378	8,328	10,421	12,992	14,467	16,323	18,178
80-84	10,096	10,924	12,504	14,543	18,632	23,568	26,554	30,301
85+	14,688	18,319	22,392	27,581	34,131	44,464	58,441	71,946
Total	41,447	47,893	56,404	67,493	81,922	100,047	120,201	140,580

Source: CSO (2008a) Population and Labour Force Projections, 2011-2041, Stationary Office, Dublin, Table 5, p. 42; EuroCoDe (2009) estimates of age/gender-specific prevalence of dementia rates.

**Table 2.10:** Actual number and projected growth in the number of people with dementia in Ireland by age group, 2006-2041 (M2F1) (n)

Age groups	2006	2011	2016	2021	2026	2031	2036	2041
30-59	2,576	2,954	3,328	3,532	3,605	3,608	3,561	3,473
60-64	983	1,209	1,331	1,492	1,658	1,799	2,030	2,351
65-69	2,258	2,766	3,401	3,751	4,219	4,707	5,191	5,897
70-74	4,130	4,584	5,670	7,025	7,792	8,802	9,850	10,851
75-79	6,716	7,436	8,438	10,633	13,306	14,897	16,933	19,071
80-84	10,096	10,988	12,646	14,778	19,036	24,157	27,358	31,436
85+	14,688	18,376	22,518	27,854	34,634	45,310	59,812	73,936
Total	41,447	48,313	57,332	69,066	84,249	103,279	124,735	147,015

Source: CSO (2008a) Population and Labour Force Projections, 2011-2041, Stationary Office, Dublin, Table 3, p. 40; EuroCoDe (2009) estimates of age/gender-specific prevalence of dementia rates.

The projections in both Tables 2.9 and 2.10 are based on the assumption that age/gender-specific prevalence rates of dementia will remain unchanged in the future.

## 2.11 Limitations of projections

These dementia prevalence projections for the period 2011 to 2041 should be interpreted cautiously as they have several limitations. First, these estimates are based on current population projections which themselves rest on uncertain assumptions. Demographic forecasting is an uncertain exercise, as population projections are hypothetical and based on the assumptions that 'if certain trends continue, this is what will happen' (Fahey and FitzGerald, 1997: 8). They, therefore, do not allow for major shifts in demography that might occur in the future. Past experience in Ireland shows that even over short periods of time, actual developments often diverge from the projections forecast (Dignan, 2009). Migration tends to be one of the most volatile components of population projections (Dignan, 2009). For example, the M0F2 projections used to calculate the estimates above assume that Ireland will be characterised by zero net migration. However, in 2010 the CSO (2010a) estimated that in the 12 month period April 2009 to April 2010 an increase in net outward migration from 7,800 to 34,500 would occur.

The Economic and Social Research Institute (ESRI) now forecasts net outward migration to be 100,000 over the two-year period from April 2010 to April 2012 (Barrett et al., 2011).

Another reason for treating these projections cautiously is because they rely on the assumption that age/gender-specific prevalence rates of dementia will remain unchanged over time. Most projections of the future numbers of people with dementia start with this assumption (Comas-Herrera et al., 2011) and long-term international studies suggest that age-specific prevalence of dementia has changed little over the last 30 to 40 years in developed countries (Prince, 2009). However, such assumptions fail to take account of other research reporting on the potential impact that preventative strategies or disease-slowing treatments may have on the future numbers of people with dementia (Brookmeyer, Gray and Kawas, 1998; Sloane et al., 2002; Brodaty, Sachdev and Anderson, 2005; Jorm et al., 2005; Jagger et al., 2009; Comas-Herrera et al., 2011).<sup>18</sup>

Accordingly, as the estimates calculated are based on several different and interrelated assumptions future dementia prevalence estimates should not be used as precise figures. Notwithstanding this, these projections are important as indications of general trends. They assist in raising awareness of the size of the challenge faced by this and future generations in Ireland in relation to dementia. In particular, the trend towards a growing number of people with dementia in Ireland highlights the need to foster the development of more responsive services for a growing population of people with dementia.

## 2.12 TILDA

According to some experts (Prince, 2009: 41), nationally representative surveys which generate data on prevalence rates provide the best information for policymaking and planning. In this context, The Irish Longitudinal Study on Ageing (TILDA), a longitudinal study of a nationally representative sample of 8,000 people aged 50 years and over living in the community in Ireland, will in the future it is hoped be used to generate useful information about dementia prevalence in Ireland. Regrettably, as it is currently designed, TILDA does not include in its sampling people who are already diagnosed with dementia. There are, nevertheless, very useful questions in TILDA on cognitive function. To assess global cognitive function, TILDA employed the Mini-Mental State Examination (MMSE) to identify the presence of cognitive impairment in older adults. The findings show that overall 1% of older adults not known or suspected to have dementia were classified as living with moderate or severe cognitive impairment, with a further 9% having mild cognitive impairment (O'Regan, Cronin and Kenny, 2011). The Montreal Cognitive Assessment Tool (MoCA),<sup>19</sup> which is increasingly used worldwide as an adjunct to the MMSE, was also administered as part of the TILDA objective measures of cognitive function in older adults. The results, however, have not yet been reported. TILDA also includes questions on self-rated memory. Other questions in TILDA of salience to this dementia research review include those on utilisation of health and social care services. Findings from questions in TILDA on physical and behavioural health (Cronin, O'Regan and Kenny, 2011) have much relevance for debates about the potentially modifiable risks factors associated with dementia.

Only two countries in the world - Canada (Canadian Study on Health and Ageing (CSHA)) and the US (Aging, demographics and memory study (ADAMS)) - benefit from the inclusion of people already diagnosed with dementia in nationally representative longitudinal studies. Both studies have proved useful in generating valuable information

<sup>18</sup> For example, Comas-Herrera et al. (2011: 27), drawing on the views of a Delphi consensus panel, point towards a small reduction in the prevalence of dementia over the next 50 years. A study from Australia estimates that if future interventions have the ability to delay the onset of dementia by as little as 6 months or as much as 5 years, the prevalence of dementia would be reduced by 6% and 44% respectively (Jorm et al., 2005). Conversely, improved medical and social care might reduce case mortality and thus increase prevalence of dementia (Ferri et al., 2005).

<sup>19</sup> The MoCA test is a screening instrument for the detection of mild cognitive impairment. It was developed to discriminate between individuals with mild cognitive impairment and those with normal cognitive function.

on the prevalence of dementia in their respective countries. In the US ADAMS survey, dementia is ‘usefully and efficiently’ studied in a detailed add-on sub-study to its ongoing nationally representative survey of ageing and health (the Health and Retirement Survey), although it is carried out on a very small sample (Prince, 2009: 41). The CSHA,<sup>20</sup> on the other hand, was originally designed as a national longitudinal study to include people diagnosed with dementia including Alzheimer’s disease. The CSHA study was ambitious in its design as it drew on representative samples from the community and from institutions, and participants were assessed over a ten-year period at five-yearly intervals. The study, which initially focused on the epidemiology of dementia, has provided estimates of prevalence, incidence and risk factors for dementia and information on family caregivers.

At EU level, it is expected that the cognitive test module in the planned European Health Examination Survey (EHES),<sup>21</sup> which is being piloted in 14 countries (excluding Ireland), will be a useful source of valuable information and data with a strong predictive value on the evolution of dementia (European Commission, 2009).

## 2.13 Incidence of dementia in Ireland

Incidence of dementia, as mentioned above, refers to the number of new cases of the condition in the population over a given period of time. Incidence rates are usually represented as the number of new cases per 1,000 persons per year. As incidence of dementia rises rapidly with age, incidence rates are rising as more and more people are living to the older age groups when dementia is more prevalent.

While there are difficulties attached to estimating prevalence of dementia, estimating the incidence of dementia is even more problematic (Alzheimer Scotland, 2000). Few international studies of incidence have produced similar results, with incidence rates ranging from between 2.5 new cases per 1,000 people over 65 to 26 new cases per 1,000 people over 65 (Alzheimer Scotland, 2000). Using a Delphi consensus study, Ferri et al. (2005: 2115) have estimated an incidence rate in Western Europe of 8.8 new cases per 1,000 persons over 60 years per year. O’Shea (2007: 11) (extrapolating lower middle-range international incidence rates to the population of older people in Ireland to make a tentative estimate of the incidence of dementia in Ireland) suggests that ‘approximately 4,000 new cases arise in the general Irish population every year’.

## 2.14 Summary and conclusion

This chapter has reviewed the relevant international literature on dementia prevalence rates both globally and at a European level and has shown that the number of people around the world likely to have dementia in 2010 was 35.6 million (Prince, 2009). In Europe the number of people currently estimated to have dementia is over 7.7 million (Alzheimer Europe, 2009). In the absence of adequate epidemiology studies of dementia in Ireland, age/gender prevalence rates (both EURODEM and EuroCoDe) have been applied to Irish Census data and new information about dementia prevalence rates in Ireland have been calculated. It has been estimated that for 2006 and based on Census data from that year there were about 41,700 people in Ireland living with dementia. This figure includes younger people but excludes a small but not insignificant number of people likely to have an Alzheimer’s type dementia associated with Down syndrome. As the life expectancy of people with intellectual disability, and particularly those with Down syndrome, continues to rise, so too will the number of people presenting with dementia. It is important that information on population demographics for this group is available to allow appropriate dementia services to be put in place to meet the expected growth in demand.

<sup>20</sup> [www.csha.ca/](http://www.csha.ca/)

<sup>21</sup> [www.ehes.info/](http://www.ehes.info/)

44 Based on EuroCoDe age/gender prevalence rates and on the Census of Population 2006 data, this chapter has provided new estimates of the prevalence of dementia at a local and regional level. Dementia affects a higher proportion of the overall population in the West than in the East, mainly because the average age of the population is higher in the West than elsewhere in the country. In proportion to the total population, there is more than twice the number of people with dementia in Roscommon than there are in Dublin West. Important information on the potential prevalence of dementia in any area or region can be gleaned from simply looking at population age structure data, making it easier to plan for service provision.

The chapter has shown that information about dementia prevalence rates in long-stay care in Ireland is patchy and unreliable. Estimates within Ireland vary from between approximately 30% of all residents, which is the official figure, to as many as 90%. The way in which data is currently collected and collated by the Department of Health for the Long Stay Activity Statistics is not useful for extrapolating reliable data on the numbers of people with dementia in residential care settings. National and international studies suggest that at least 50% of nursing homes residents are people with dementia. A review of the way in which data on dementia is collected, collated and presented in the Annual Long-Stay Activity Statistics Report should be undertaken with a view to generating more reliable estimates of the number of people with dementia in long-stay care in Ireland.

As part of this review, new projections on future dementia prevalence rates in Ireland over the next 30 years, i.e. until 2041, have been calculated based on two different population projection methodologies. The calculations show that the number of people with dementia is set to rise from an estimated 41,447 in 2006 to between 67,500 and 70,000 in 2021 and to between 140,500 to 147,000 in 2041. Because of the limitations attached to estimating population forecasts and predicting future prevalence rates of dementia, these figures should be interpreted with caution.

TILDA does not currently study dementia. However, TILDA would offer an opportunity for studying the prevalence of dementia in Ireland, if it were to adopt the approach used in nationally representative surveys in other countries such as the ADAMS study in the US or the CSHA study in Canada, both of which actively seek to include people with dementia in their surveys. People known or suspected to have dementia and people residing in nursing homes could be recruited as participants in the next and subsequent waves of data collection for TILDA.

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Photo: Ken Finegan

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# CHAPTER 3

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## THE ECONOMIC AND SOCIAL COSTS OF DEMENTIA IN IRELAND

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The allocation of resources to dementia is ultimately a political decision that can be influenced by stakeholders and public opinion.

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# CHAPTER 3

## The economic and social costs of dementia in Ireland\*

### 3.1 Introduction

Dementia is a costly condition and one that differs somewhat from other conditions in the way that its costs are distributed. The recent World Alzheimer Report estimated the worldwide cost of dementia to be in the region of US\$604 billion (Wimo and Prince, 2010): 42% of these costs were attributable to informal or unpaid care provided by family and friends in the community, while a further 42% were due to care provided in residential settings; only 16% of total costs were attributable to dementia-related direct health care costs. Wimo et al. (2011), examining the economic impact of dementia in Europe, found that the total cost of dementia disorders were in the region of €160 billion, 56% of which was attributable to the costs of informal care. The average cost per person with dementia was estimated at approximately €22,000 per year, though significant variations were observed across countries.

A number of studies have highlighted the significant costs associated with dementia in particular countries (Cavallo and Fattore, 1997; Érsek et al., 2010; Jönsson et al., 2006). In the UK, dementia-related costs amounted to just over Stg£17 billion (€19.9 billion) for 2005/6, with costs varying significantly depending on the severity of disease. A subsequent UK study found the total cost of dementia to be in the region of Stg£23 billion (€26.9) (Luengo-Fernandez et al., 2010). In Ireland, the annual cost per person with dementia was estimated to be IR£8,261 in the later 1990s, aggregating to a total annual cost of IR£248 million (O'Shea and O'Reilly, 2000). Formal care accounted for 50% of total costs, while residential care was responsible for 33% of costs.

The predicted increase in the number of older people in Ireland will result in a significant increase in the number of people with dementia in the coming years. At present, despite Government policy about supporting people to remain in their own home, community-based services for people with dementia are partial and fragmented, resulting in a significant proportion of those with dementia having little option but to seek admission to long-stay residential care. This has significant budgetary implications, given the very high cost of residential care. For those remaining in the community, the burden of care largely falls on family and friends, imposing significant costs on caregivers. Moreover, without adequate support for caregivers and the development of community-based services, continued reliance on informal care may be unsustainable in the longer term.

Cost of illness studies are a useful way to document the origins and extent of resource use in relation to particular diseases. They require the identification, measurement and valuation of all resources related to a particular disease. The output, expressed in monetary terms, is an estimate of the total cost of a particular disease to society (Rice, 1994). Cost of illness studies are not without their critics, both in terms of their methodology (Drummond, 1992) and their usefulness (Byford et al., 2000). For example, identifying a high level of expenditure for a particular disease or condition does not give any indication of how efficiently resources are being used and provides little information on how priorities should be set. Nonetheless, cost of illness studies are useful in determining not only resource use, but also the distribution of costs among different resource categories. The aim of this chapter is to provide an estimate of the economic and social costs of dementia in Ireland in 2010.

### 3.2 Data and methodology

The cost of dementia in Ireland was estimated across four main resource categories:

- > informal care for people with dementia living in the community
- > formal health and social care in primary, community, acute and psychiatric settings
- > residential long-stay care
- > premature mortality from dementia.

\* Thanks to Sheelah Connolly and Paddy Gillespie for their work on this chapter.

Different perspectives can be used when conducting cost of illness studies, with the perspective adopted determining the categories of costs included in the analysis. A health services perspective, for example, would only include those costs falling directly on health services budgets, for example, pay costs in hospital-based care settings. A societal perspective is broader and includes, as far as possible, all costs, regardless of where they fall. In addition to health service costs, such an approach would include the opportunity cost associated with unpaid care to people with dementia by family caregivers and productivity losses associated with premature death (Luengo-Fernandez et al., 2010). In this report a societal perspective has been adopted in an attempt to comprehensively capture the cost of dementia on the patient, their caregiver and the state.

Cost of illness studies can adopt either a top-down approach (using national data) or a bottom-up approach (using local or survey data extrapolated to the national level). Given the lack of available national data, it has been necessary to adopt both approaches to generate the estimates used in this chapter. The measurement process was significantly complicated by the lack of nationally available data on the number and distribution of people with dementia across various care settings in Ireland, as well as the absence of a comprehensive database on resource use for people with dementia and associated unit costs. Consequently, we have had to be imaginative and eclectic in drawing on all available information, some of which were far from complete, suggesting that caution is necessary in interpreting the various estimates generated with respect to resource use and costs.

An annual time frame was adopted, with all costs due to dementia estimated for the most recent year for which data was available. All unit costs are presented in Euro (€) currency, using 2010 as the base year. Where necessary, cost estimates extrapolated from an earlier period have been adjusted using an appropriate inflation index (CSO, 2010b). Finally, where possible, dementia is defined by international classification of disease (ICD)-10 code incorporating F00 (Dementia in Alzheimer's disease), F01 (Vascular dementia), F02 (Dementia in other diseases classified elsewhere), F03 (Unspecified dementia) and G30 (Alzheimer disease). However, in cases where this was not possible alternative approaches were used to identify people with dementia, as will be evident later in the chapter.

### 3.2.1 Resource Use

In Chapter 2, we presented prevalence estimates which suggested that there are a total of 41,740 people with dementia in Ireland, of whom 3,583 are aged less than 65 years. To follow the methodology presented above, it was necessary to have estimates of the number of people with dementia across different care settings. However, this information is not yet officially available in Ireland. In this section, the number of people with dementia living in various care settings will be estimated and their associated resource use documented.

#### (i) Informal care in the community

The majority of people with dementia in Ireland live in the community. Estimates of the number of people living in the community with dementia are derived by applying age-specific dementia rates for those aged 65 and over (Lawlor et al., 1994) to the most recently available population estimates from the Census of Population. Table 3.1 shows that there are an estimated 23,058 people with dementia aged 65 years and over living in the community. Additionally in Chapter 2, it was shown that there are an estimated 3,583 people aged less than 65 years with dementia. Previous work has shown that 15% of younger people with dementia reside within a residential care setting (Haase, 2005); therefore, for the purpose of this analysis it is assumed that 3,046 of those aged less than 65 with dementia live in the community, with the remainder (537) assumed to be in a long-stay setting. Therefore, there are a total of 26,104 people with dementia estimated to be living in the community.

**Table 3.1:** Number of older people aged 65 and over living in the community with dementia

Age-group	Percentage in community with dementia*	Population in the community†	Number with dementia
65-69	1.6	136,048	2,177
70-74	4.8	111,727	5,363
75-79	2.1	84,086	1,766
80-84	10.4	55,419	5,764
85+	22.9	34,882	7,988
All	5.5		23,058

Source: \* Lawlor et al. (1994); † CSO (2007b)

The majority of community-dwelling people with dementia are cared for by family and friends. There are a few small-scale, local studies which give estimates of the amount of care provided by informal caregivers to people with dementia living in the community in Ireland. For example, O’Shea (2003) identified 98 caregivers of people with dementia through the ASI and found that, on average, they were providing 11.6 hours of care per day. A more recent study of 100 participants, identified from referrals to a memory clinic with a diagnosis of probable or possible Alzheimer’s disease or mild cognitive impairment found that on average participants received 5.06 hours of informal care per day (Gallagher et al, 2010). The difference in the amount of care hours received between the two studies is most likely explained by the severity of dementia, with those in the former study at a more advanced stage than those in the latter study. For the purpose of this analysis, an average of the two numbers (8.33 hours per day) is used to estimate mean care provision for people with dementia living at home in the community. This is likely to be an underestimate of the number of informal care hours received, as one of the first studies in this area (Ruddle and O’Connor, 1992) suggested that the average care provision for people with dementia was 11 hours per day, which is closer to the O’Shea’s (2003) estimate. In any case, we incorporate the higher figure in our sensitivity analysis later in the chapter.

**(ii) Formal health and social care in primary, community, acute and psychiatric settings**

Community-based care: Data on formal primary care, community care and out-patient hospital care for people with dementia living in the community is derived from the Enhancing Care in Alzheimer’s Disease (ECAD)<sup>22</sup> study (Gillespie et al., under review). In that study, data on service utilisation was collected over a six month period for each study participant. Services included: General Practitioner (GP) consultations; dementia-related respite care; meals on wheels; contacts with a registered nurse, physiotherapist, psychologist, chiropodist, occupational therapist, social worker and home help; out-patient consultations; and accident and emergency admissions. Observed utilisation rates were annualised and applied to the projected number of people with dementia living in the community to estimate overall resource use.

Estimates of the proportion of people living with dementia in the community who are taking anti-dementia (i.e. donepezil, galantamine, rivastigmine, memantine), anti-psychotic (i.e. quetiapine), anti-depressant (i.e. citalopram hydrobromide, duloxetine), and anti-anxiety (i.e. alprazolam) medications were based on figures from the same ECAD study (Gillespie et al, under review). Normal dosage levels were taken from Monthly Index of Medical Specialities (MIMS) and applied pro-rata to the number of people with dementia estimated to be taking the various drugs (See Table 3.9).

<sup>22</sup> The ECAD study is an observational study conducted in 2009 of 100 community dwelling individuals with Alzheimer’s disease or mild cognitive impairment in Dublin.



Acute hospital care: The number of day-case and number of in-patient discharges where dementia was regarded as the main diagnosis occasioning admission were derived from the HIPE Scheme for 2009. HIPE is a computer-based system designed to collect demographic, clinical and administrative data on discharges and deaths from acute hospitals nationally. The associated average lengths of stay are derived from the same source. In 2009, there were 644 in-patient discharges and 141 day-cases in acute hospitals where dementia was the principal diagnosis occasioning admission.

However, these figures are likely to be significant underestimates of the number of in-patient and day-case admissions associated with dementia. HIPE data shows that there were 6,644 in-patient and 324 day-case admissions where dementia was either a primary diagnosis for admission or an additional or secondary diagnosis. Dementia as a secondary diagnosis can significantly contribute to the cost of admission by increasing length of stay (Lyketsos et al., 2000). Ideally, the additional cost associated with a secondary dementia diagnosis would be included in the calculation of overall costs; however, given data limitations it is not possible to estimate marginal dementia costs for acute care in an Irish context, although we do include an estimate in the sensitivity analysis.

Psychiatric care: Information on people with dementia in long-stay psychiatric hospitals and units, including average length of stay was obtained from the National Psychiatric In-Patient Reporting System (NPIRS) for 2009. There were 456 psychiatric admissions due to dementia in that year, 60 of which were for people under 65 years of age.

**(iii) Residential Long-Stay Care**

As mentioned earlier, there are an estimated 41,470 people with dementia in Ireland; of whom 26,104 reside in the community, 644 in acute care and 456 in psychiatric care. Assuming that the remainder all live in long-stay residential care suggests that there are 14,266 people with dementia in various long-stay facilities throughout the country (Table 3.2), including 537 people aged less than 65 years.

**Table 3.2: Distribution of people with dementia across care settings in Ireland**

Care Setting	Number	(%)
Community	26,104	(63%)
Acute care	644	(2%)
Psychiatric care	456	(1%)
Long stay residential care	14,266	(34%)
All	41,470	

According to the Department of Health’s Long-Stay Activity Statistics, there are 22,613 people in long-stay units (Department of Health and Children, 2009). Our estimate of 14,266 for the number of residents with dementia in long-stay facilities suggests that 63.1% of those people have dementia. This is significantly higher than the official estimate of the Department of Health, which suggests that only 26% of people in long-stay units have dementia (Department of Health and Children, 2009). However, the latter is generally recognised as an underestimate and our calculation, for all its imperfections, is more in line with international evidence, which suggests that between 60% and 70% of long-stay residents have dementia (Helmer et al., 2006; Knapp and Prince, 2007). Indeed, recent evidence from Ireland has shown that 89% of nursing home residents have some level of cognitive impairment, with 42% having severe cognitive impairment (Cahill and Diaz-Ponce, 2010). While the latter study was based on relatively small numbers and cognitive impairment does not necessarily equate with dementia, it does suggest a significant under-representation of dementia in official long-stay statistics.

There are five main types of long-stay residential settings in Ireland: HSE Extended Care Units; HSE Welfare Homes; Voluntary Homes; Voluntary Welfare Homes and Private Nursing Homes. Based on the assumption that 63.1% of long-stay residents have dementia in all settings, Table 3.3 shows the number of people with dementia in each setting. While the assumption of eqi-proportionality across care settings is strong, it is equally problematic to base the relative proportion of dementia patients in each care setting on data from the Department of Health, given the concern about the difficulties associated with the official returns in relation to diagnosis.

**Table 3.3:** Number of long-stay residents and percentage with dementia in Ireland, 2008

Type of Unit	Number of Residents*	Percentage with dementia	Number with dementia
HSE Extended Care Unit	5,884	63.1	3,712
HSE Welfare Home	829	63.1	523
Voluntary Home/Hospital	1,698	63.1	1,071
Voluntary Welfare Home	376	63.1	237
Private Nursing Home	13,826	63.1	8,722
All	22,613		14,266

Source: \* Department of Health and Children (2009).

**(iv) Premature mortality from dementia**

The fourth main category used to estimate the total cost of dementia in Ireland relates to lost productivity due to premature mortality. This involves calculating the foregone earnings from premature death associated with dementia. Data on the number of deaths of younger people with dementia in 2010 broken down by five yearly age groups (i.e. 50-54, 55-59 and 60-64) were obtained from the CSO. It was assumed that the proportion of people with dementia aged 65 years of age still working is negligible, so these people were excluded from the analysis. The total number of working years lost due to premature dementia-related deaths was calculated for each of the three age groups, relative to normal retirement age (Table 3.13). The next step involved calculating the cost of working years lost using average annual earnings for 2010 (CSO, 2011b). As these productivity costs would be incurred in future years, all future foregone earnings were discounted using a rate of 4% per annum, following current Irish guidelines for health technology assessment (HIQA, 2010). Average annual earnings data were applied to the total working years lost for each of the three age groups to generate the total loss of earnings (productivity losses) associated with dementia.

**3.2.2. Unit costs**

Table 3.4 shows the unit cost estimates applied to various resources to determine the overall cost of dementia. There is, in general, in Ireland a paucity of data relating to unit costs for various health and social services; this is especially so when looking at specific illness or conditions in relation to older people. Consequently, in estimating costs for this study, it is necessary, in many instances, to use generic, age-related cost estimates rather than dementia-specific estimates.

Unit costs for primary, community and hospital-based care are derived from a variety of published and unpublished national sources. Hospital-based cost estimates are derived from case-mix data from the Department of Health. Case-mix categorises and quantifies the mix of cases within hospitals by classifying patients into discrete classes or groups (diagnostic related groups (DRGs)) which share common clinical attributes and similar patterns of resource use. Average costs are then assigned to each of the DRGs (Department of Health and Children, 2003). For visits to specialists, estimates of the costs per consultation are based on the published salary scales of the appropriate health and social care professional. A period of 30 minutes per consultation is assumed for the calculation of costs. For medications, a weighted average daily cost is estimated for each drug category from the range of available

brands, based on recommended daily dosage. Unit cost data are taken from the 2010 version of the MIMS Ireland catalogue.

Cost per resident in long-stay residential care is based on the maximum weekly financial support available from the HSE under the Nursing Home Support Scheme (NHSS), which provides financial support for people assessed as needing long-term nursing home care. The HSE provides differential price support for the cost of care in (i) public long-stay facilities; and (ii) private and voluntary long-stay facilities, a distinction which is reflected in this study.

Informal care from family and friends provided to people with dementia is generally free of charge; however, this does not mean that it is without value. In our analysis, an opportunity cost approach is used to place an economic value on the informal care of people with dementia. Opportunity cost is a measure of the economic sacrifice that caregivers make to provide unpaid care for their spouse, friends or relative suffering from dementia (Luengo-Fernandez et al., 2010). Not all caregivers make economic sacrifices in order to care for loved ones, which is the reason why estimates of the opportunity cost associated with informal caregiving are derived separately in this study for those in employment and those not in employment.

Data from the ECAD study (Gillespie et al., under review) on the labour force participation status for each caregiver are used to categorise caregivers as either employed (29%) or not employed (71%). For the employed group, the opportunity cost of caring is valued at the average industrial wage in Ireland in 2010 (21.81 per hour) mainly because the average weekly number of paid hours worked was only 29, suggesting that if people were not caring they could potentially be engaged in further paid work. Of those not in employment and caring, almost all were not actively seeking employment, having reached retirement age, taken early retirement, had never engaged in paid work, or had health-related problems. For this group, the opportunity cost of time is valued as a percentage (25%) of the average industrial wage equal to €5.45 per hour, on the assumption that only leisure time is sacrificed in order to care.

An alternative approach for valuing informal care is the replacement cost method, whereby carer time-input is costed at the level of remuneration required to hire an equivalent paid professional to replace the carer. This method is not adopted in the base-case analysis as the opportunity cost approach is more consistent with economic theory (McDaid, 2001). In the sensitivity analysis, a replacement cost based on the hourly rate of a health care assistant is applied to value carer hours.

Table 3.4: Unit cost estimates

Resource Activity	Activity	Unit Cost (€)	Source
<b>Primary, Community and Hospital Care</b>			
General Admission	Per Night	809	Casemix Unit, DoHC
Psychiatric Admission	Per Night	339	Casemix Unit, DoHC
Accident & Emergency (A&E) Admission	Per Admission	265	Casemix Unit, DoHC
Day-Case Admission	Per Admission	711	Casemix Unit, DoHC
Geriatrician Visit (Outpatient Clinic)	Per Visit	156	Casemix Unit, DoHC
Neurologist Visit (Outpatient Clinic)	Per Visit	156	Casemix Unit, DoHC
Psychiatrist Visit (Outpatient Clinic)	Per Visit	156	Casemix Unit, DoHC
General Practice (GP) Visit	Per Visit	50	Smith et al. (2010)
Physiotherapist Visit	Per Visit	28	Salary Scales, DoHC
Occupational Therapist Visit	Per Visit	28	Salary Scales, DoHC
Other Specialist Visit	Per Visit	28	Salary Scales, DoHC
Respite Day Care Service	Per Visit	97	O'Shea and Kennelly (2008)
Home Help Service	Per Visit	18	Salary Scales, DoHC
Meals on Wheels Service	Per meal	7	O'Dwyer and Timonen (2008)
Registered Nurse Visit	Per Visit	32	Salary Scales, DoHC
Social Worker Visit	Per Visit	28	Salary Scales, DoHC
Anti-Dementia Drugs	Per Day	1.88	Monthly Index of Medical Specialities Ireland (MIMS IRE)
Anti-Depressant Drugs	Per Day	0.59	MIMS IRE
Anti-Anxiety Drugs	Per Day	0.04	MIMS IRE
Anti-Psychotic Drugs	Per Day	3.33	MIMS IRE
<b>Residential Care</b>			
Public Nursing Home	Per Week	1245	DoHC/HSE
Private and Voluntary Nursing Home	Per Week	876	DoHC/HSE
<b>Informal Caregiving</b>			
Caregiving by person in employment	Per hour	22	Central Statistics Office www.cso.ie
Caregiving by person not attached to the labour force	Per hour	5	Central Statistics Office: www.cso.ie
Health Care Assistant	Per hour	33	DoHC/HSE
<b>Mortality</b>			
Working Year Lost (Human Capital Approach)	Per Year	29,113*	Central Statistics Office: www.cso.ie

Note: Unit costs are presented in 2010 prices. Where necessary, unit costs were inflated using the medical component of the consumer price index (www.cso.ie) \*Future earnings discounted at an annual rate of 4%

### 3.2.3 Sensitivity analysis

The impact of uncertainty in relation to both resource use and unit costs is explored using sensitivity analysis. There are significant sources of uncertainty relating to the number and distribution of people with dementia in both acute general hospitals and in residential care settings. In the base case analysis, it was assumed that of the 41,740 people with dementia in Ireland, 26,104 live in the community and 14,266 in long-stay units, with the remainder in acute or psychiatric in-patient care. In the sensitivity analysis, an alternative distribution is assumed based on the Department of Health estimate of 5,879 residents in long-stay units having dementia (Department of Health and Children, 2009). Assuming that the numbers of people with dementia living in acute and psychiatric care remain the same, this increases the number of people with dementia estimated to be living in the community to 34,491 (Table 3.5).

**Table 3.5** Distribution of people with dementia across care settings in base case analysis and sensitivity analysis

	Base case	Sensitivity analysis
Community	26,104	34,491
Psychiatric care	456	456
Acute care	644	644
Long stay residential care	14,266	5,879
All	41,470	41,470

The sensitivity analysis is also used to explore other changes to both resource use and unit costs as follows:

- Informal care hours received per day is reduced and increased to 5 and 11 hours respectively
- Primary and community care use is adjusted for severity of dementia
- All caregiving hours are valued at the leisure time rate (€5.45 per hour)
- Replacement cost value is applied to all caregiving hours: valued at health care assistant hourly wage rate (€33 per hour)
- Productivity losses are adjusted for an unemployment rate of 13.6%
- 100% uptake of anti-dementia drugs is assumed
- Acute care costs are estimated for all cases where dementia is referenced as a primary or secondary diagnosis.

## 3.3 Results

### 3.3.1 Informal care in the community

Assuming that people with dementia living in the community receive just over 8 hours of informal care per day, a total of 81 million hours of care are provided by family and friends each year. Using an opportunity cost approach, and assigning different values to care provided by those in employment and not in employment, the weighted average cost of informal care is estimated to be €10 per hour. Informal care for those with dementia is therefore estimated to be €807 million per annum (Table 3.6).

**Table 3.6** Informal care for people with dementia living in the community\*

	Number with dementia in the community	Care hours per day	Cost per hour (€)	Total annual cost (€)
<65	3,046	8.33	10	92,627,309
65-69	2,177	8.33	10	67,489,634
70-74	5,363	8.33	10	166,273,983
75-79	1,766	8.33	10	54,747,957
80-84	5,764	8.33	10	178,696,872
85+	7,988	8.33	10	247,663,374
All	26,104			807,499,128

\*All calculations have been done in Microsoft Excel, numbers may not add up exactly due to rounding in the presented tables

### 3.3.2 Formal health and social care in primary, community, acute and psychiatric settings

#### (i) Primary and community care

Primary and community care resource use for people with dementia is shown in Table 3.7. The most commonly used services include: respite care, home help visits and meals on wheels, with relatively little use of occupational therapists and social workers. In total, the annual cost of primary and community care for those with dementia was €65 million, 59% of which was accounted for by respite care.

**Table 3.7** Primary and community resource use for people with dementia living in the community

	Average visits/usage per person with dementia	Number with dementia in community	Total Annual usage	Unit cost (€)	Total cost (€)
GP Visit	4.40	26,104	114,858	50	5,742,880
Physiotherapist visit	0.38	26,104	9,920	28	279,636
Occupational therapist visit	0.16	26,104	4,177	28	117,741
Social Worker Visit	0.16	26,104	4,177	28	117,741
Other (specialist) visit	0.68	26,104	17,751	28	500,401
Respite day care	15.20	26,104	396,781	97	38,570,437
Home Help visit	32.80	26,104	856,211	18	15,813,879
Meals on Wheels	12.40	26,104	323,690	7	2,202,575
Registered Nurse visit	2.00	26,104	52,208	32	1,674,769
All					65,020,059

**(ii) Outpatient care**

Table 3.8 shows the average out-patient use per person with dementia living in the community, with its associated unit cost. The total annual cost comes to almost €7.3 million, with the largest proportion due to Accident and Emergency (A&E) use (36%).

**Table 3.8** Out-patient care for people with dementia living in the community

	Average number of visits per person with dementia	Number with dementia in community	Total Annual use	Unit cost (€)	Total cost (€)
Accident & Emergency visit	0.38	26,104	9,920	265	2,632,432
Geriatric visit (outpatient clinic)	0.50	26,104	13,052	156	2,030,023
Neurology Visit (Outpatient clinic)	0.12	26,104	3,132	156	487,206
Psychiatrist Visit (outpatient clinic)	0.52	26,104	13,574	156	2,111,224
All					7,260,885

**(iii) Medications**

Approximately 75% of people with dementia living in the community are prescribed an anti-dementia drug, with a significantly smaller proportion receiving anti-depressant, anti-anxiety, or anti-psychosis drugs (Table 3.9).

The total cost associated with dementia related medication is almost €16 million, of which 85% is accounted for by anti-dementia drugs.

**Table 3.9** Dementia-related medication use among those living in the community

	% of dementia population on drug	Number of dementia population on drug *	Annual cost of drug (€)	Total annual cost (€)
Anti-dementia drugs	75	19,678	688	13,469,664
Anti-depressant drugs	9	2,349	214	502,763
Anti-anxiety drugs	4	1,044	15	15,245
Anti-psychosis drugs	6	1,566	1,216	1,904,548
All				15,892,220

\*Assuming there are 26,104 people with dementia living in the community

**(iv) Acute hospital care**

There were 605 in-patient admissions and 132 day-cases for people with dementia aged 65 years and over in 2009 where dementia was regarded as the principle diagnosis occasioning admission (Table 3.10). The average length of stay per in-patient admission was just over 42 days, with patients aged 75-84 having the longest length of stay. At an average cost of €809 per in-patient admission night and €711 per day-case, the total cost for dementia in acute hospitals came to just over €21 million per annum.

**Table 3.10** In-patient and day-case admissions with dementia as the principal diagnosis

	No of in-patient admissions	Average length of stay	No of day-cases	Average cost per in-patient night (€)	Average cost per day-case (€)	Total annual cost (€)
65-74	112	42.1	45	809	711	3,845,508
75-84	292	46.6	56	809	711	11,044,944
85+	201	38.0	31	809	711	6,199,445
All	605		132			21,089,897

**(v) Psychiatric in-patient care**

Table 3.11 shows the number of discharges and the average length of stay associated with psychiatric in-patient care for people with dementia. In 2009, there were 456 discharges or deaths, of which 41% were to those aged 75 to 84. The average length of stay was 265 days, with the longest length of stay observed for those aged 85 and over. With an average nightly cost of €339, the total annual cost of psychiatric in-patient care for those with dementia is €38,684,162.

**Table 3.11** Psychiatric in-patient care for people with dementia

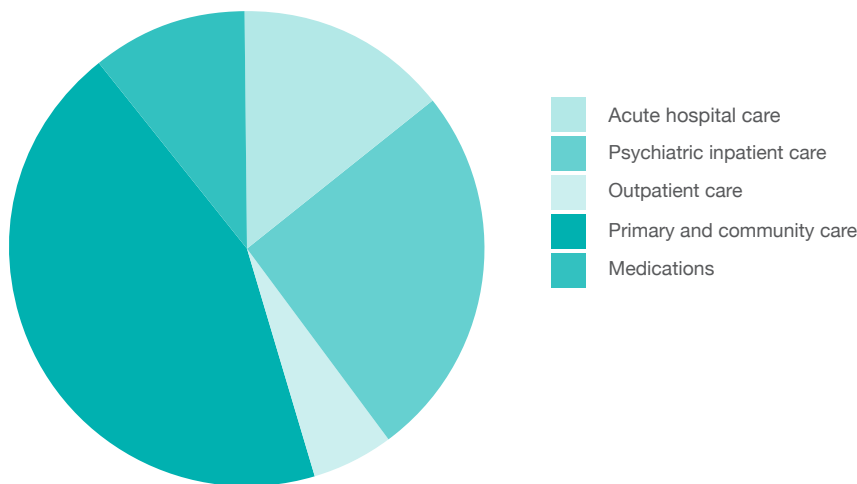
	Number of discharges (including deaths) *	Average length of stay by discharge (days) *	Average daily cost per inpatient bed (€)	Total annual cost (€)
<65	60	103	339	2,098,239
65-74	115	167	339	6,517,389
75-84	188	291	339	18,552,441
85+	93	365*	339	11,516,093
All	456	265		38,684,162

\*The average length of stay for those aged 85 and over was 440.48 days. However, as this analysis is concerned with estimating the annual cost associated with dementia, this has been changed to 365 days, reflecting the longest possible length of stay in a given year.



Combined formal health and social care costs came to €147,947,223 in 2010. Figure 3.1 below shows the distribution of formal health and social care costs by category. By far the most significant proportion is primary and community care, accounting for 44% of all health and social care costs; psychiatric care accounts for 26% of all costs, while acute hospital care accounts for 14%.

Figure 3.1 Dementia-related health and social care cost by category



### 3.3.3 Residential long-stay care

With an estimate of 14,266 people with dementia in long-stay care, Table 3.12 shows the annual cost of care for various types of residential care. The total cost of all residential care is estimated to be €731 million for 2010, suggesting an average cost per resident of €51,251 per annum. We have not included any continuing community-based entitlements of residents in these calculations. Private provision accounts for almost 67% of all dementia-related residential care costs. While the average weekly cost of private nursing home care is less than that in public homes, more people with dementia reside in private nursing homes.

Table 3.12 Cost of dementia in residential long-stay care

	Number with dementia	Weekly cost of care (€)	Total annual cost of care (€)
HSE Extended care Unit	3,712	1245.37	240,383,114
HSE Welfare Home	523	1245.37	33,867,709
Voluntary Home	1,071	875.97	48,793,257
Voluntary Welfare Home	237	875.97	10,804,632
Private Nursing Home	8,722	875.97	397,300,104
All	14,266		731,148,816

### 3.3.4 Productivity losses associated with premature death

The costs associated with lost productivity due to mortality comprise the foregone earnings from premature death due to dementia (Table 3.13). There were 28 dementia-related deaths before the age of 65 recorded in Ireland in 2010. The number of working years lost due to premature mortality is estimated by combining expected working years remaining by age group with the number of deaths in that age group. Discounted annual earnings for each age group is estimated by multiplying average annual earnings by the number of potential working years lost. In total, the loss of earnings due to premature dementia-related mortality is €4.3 million.

**Table 3.13** Productivity losses associated with premature mortality from dementia

	Dementia related deaths	Working years lost*	Discounted annual earnings (€)	Total loss of earning (€)
50-54	6	13	22,860	1,783,093
55-59	7	8	25,031	1,401,719
60-64	14	3	27,495	1,154,778
All	28	24		4,339,591

\*Assuming age to be mid-point of range and retirement at 65

### 3.3.5 Total cost of dementia in Ireland

The estimated annual baseline cost of dementia in Ireland in 2010 is over €1.69 billion (Table 3.14). Just under half of the total cost (48%) is accounted for by informal care provided by family and friends to people with dementia living in the community, while 43% is due to residential long-stay care. Formal health and social care provision, linked mainly to primary and community care, comprises only 9% of the total cost of dementia. With an estimate of 41,740 people with dementia living in Ireland, the average annual cost per person with dementia is estimated to be €40,511.

**Table 3.14** Total cost of dementia in Ireland, 2010

	Total cost (€)	% of total cost
Informal care	807,499,128	48%
Formal health and social care	147,947,223	9%
Long-stay care	731,148,816	43%
Premature mortality	4,339,591	<1%
Total Cost	1,690,934,758	

### 3.3.6 Sensitivity analysis

Table 3.15 shows the impact on the total cost of dementia and the distribution of costs of varying some of the estimates used in the analysis.

**Table 3.15** Sensitivity analysis around uncertain estimates used in the analysis

	Impact on total cost (€)	Impact on distribution of costs
Base case analysis	1,690,934,758	
Number with dementia in long stay care = 5,879; number in community with dementia = 34,491	-160,342,518	Residential care accounts for 20% of costs; informal care for 69% and health for 12%
Number of informal care hours received per day – 5	-322,807,381	Informal care accounts for 37% of dementia-related costs
Number of informal care hours received per day – 11	+ 258,826,251	Informal care accounts for 55% of dementia-related costs
Primary & Community care usage–based on patients with moderate or severe dementia	+ 27,256,772	Health care costs account for 10% of total costs
Care hours – all valued at leisure rate - €5	-410,666,830	Informal care accounts for 31% of total costs
Care hour – valued at replacement care assistant rate	+1,811,594,037	Informal care accounts for 75% of total costs
Working years lost – assume 13.6% unemployment	-591,798	Productivity losses continue to account for less than 1% of total costs
Anti-dementia drugs – assume 100% uptake	+4,488,199	Health care costs still account for 9%
Dementia as any diagnosis in acute care	+109,629,360	Health care accounts for 14% of total costs

Changing the distribution of people with dementia across care settings to 5,879 people (which is the official estimate of the number of people with dementia in residential care) in long-stay units and 34,491 in the community decreases the total cost of dementia by €160 million per annum. More significantly, it has implications for the distribution of costs, with long-stay care now accounting for only 20% of costs (compared to 43% in the base case) and informal care rising to 69% of costs (compared to 48% in the base case).

Increasing the number of informal care hours received by people with dementia living in the community has a significant impact on costs; increasing the amount of care received to 11 hours a day raises the total cost of dementia to €1.95 billion, with informal care now accounting for 55% of all costs. Conversely, reducing the number of informal hours of care received to 5 reduces overall costs by almost €323 million per annum. Applying a replacement health care assistant salary cost to all care hours provided would increase total costs by €1.8 billion, more than doubling the total costs associated with dementia. Conversely, applying a rate of €5 per hour of care to all informal care hours would reduce overall costs by €411 million.

Varying the formal health and social care estimates has little impact on the overall cost estimates, given their relatively small contribution to overall costs. However, including older people in acute care with a secondary diagnosis of dementia raises overall costs by almost €110 million per annum.

### 3.4 Summary and conclusion

This study has estimated the overall cost of dementia in Ireland to be just over €1.69 billion per annum, 48% of which is attributable to informal care provided by family and friends to those living with dementia in the community. A further 43% is accounted for by residential long-stay care, while formal health and social care services contribute only 9% to the total costs of dementia. Assuming there are 41,470 people with dementia, this suggests an average cost per person of approximately €40,500. The considerably higher cost estimated in this study relative to earlier estimates for Ireland (O'Shea and O'Reilly, 2000) likely reflects the significant increase in costs over the past decade, a more realistic assumption of the prevalence of dementia in long-stay settings and more comprehensive information on resource use and associated unit costs for both formal and informal care.

The sensitivity analysis explored the impact of varying key estimates. If a greater proportion of dementia patients were assumed to be living in the community rather than long-stay care, the total costs associated with dementia decrease by almost 10%. However, increasing the number of informal care hours received from 8 (as assumed in the base case) to 11 (a reasonable estimate for those with moderate to severe dementia), increases the total cost of dementia by 15%. Valuing caregivers at the replacement average wage rate for a care assistant more than doubles the overall cost of dementia in Ireland. However, varying unit costs or use of various primary, secondary and community based health services has a relatively small impact on the overall cost result, given the relatively weak contribution of health and social care to overall dementia costs. Including people in acute care with a secondary diagnosis of dementia raises costs significantly.

The results reported here are broadly in line with those from other international studies. Wimo et al. (2011) found the cost per person with dementia in Northern Europe (to which Ireland was grouped) to be in the region of €36,000 in 2008 prices; while in the UK the average cost per person with dementia in 2005/6 was found to be over £25,000 (equivalent to approximately €29,000) (Knapp and Prince, 2007). The distribution of dementia-related costs across sectors reported in this study is also in line with estimates from other countries. In our study, informal care accounts for 48% of baseline total costs; similarly, a study from the UK found informal care to be responsible for 55% of total costs of dementia care (Luengo-Fernandez et al., 2010), while a recent European study found that 56% of total costs are due to informal care (Wimo et al., 2011).

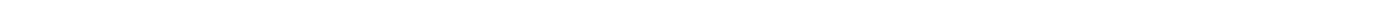
Relatively few cost of illness studies have been carried out in Ireland, making it difficult to compare the economic cost of dementia with other conditions or diseases. However, from the limited number of studies that have been completed, it appears that dementia is associated with a relatively high economic burden. While O'Shea and Kennelly (2008) estimated the total economic and social cost of mental illness to be over €3 billion in Ireland in 2006, their analysis relates to a much broader collection of conditions and diseases than included in our current work. Looking at more specific illnesses, the overall cost of falls and fractures for people aged 65 and over in Ireland was estimated

to be €404 million (Gannon et al., 2008), while the cost of schizophrenia has been estimated to be in the region of €460 million (Behan et al., 2008). Smith et al. (2010) quantified the total direct and indirect costs associated with stroke to be between €489 million and €805 million in Ireland in 2007; almost 71% of which was attributable to direct costs, the largest component being nursing home care; while informal care accounted for less than 10% of overall costs. While it is difficult to accurately compare across cost of illness studies, given the different methods and timeframes used, our results suggest a significant economic cost of dementia relative to other conditions. This has been confirmed in a UK analysis (Luengo-Fernandez et al, 2010) which, using a similar methodology to cost a number of conditions, found the economic and social costs of dementia (£23 billion (equivalent to €27 billion)) to be significantly higher than that for cancer (£12 billion (€14 billion)), heart disease (£8 billion (€9.4 billion)) and stroke (£5 billion (€5.9 billion)).

There are some limitations to the present analysis. In many instances, there is a deficiency of appropriate data on the number of people with dementia, their resource use and the associated unit costs. For example, it is generally accepted that the number of people with dementia in long-stay residential units is greater than that suggested in the Department of Health's statistics and our manufactured and extrapolated estimates reflects the general unease among researchers about using the official figures. Given the lack of national data on caregivers, it was also necessary to extrapolate data from small-scale studies to the national level to obtain an estimate of the overall involvement of family and friends in the provision of care. However, it is likely that these small-scale studies are themselves subject to bias and, therefore, should be treated with caution when generalised to the wider population of people with dementia.

Another potential limitation of the analysis relates to the valuation applied to informal care provided by family and friends. While such care is generally provided free of charge, this does not mean it is without value and should not be included in a cost of illness study. An opportunity cost approach was adopted in this analysis with a higher rate per hour assigned to people in employment than those not currently in employment who remain detached from the labour market for whatever reason (e.g. retirement, ill health, home-making). Not surprisingly, considerable controversy surrounds the use of the opportunity cost approach to value caregiver time. An alternative approach, the replacement method, values carer time-input at the level of remuneration required to hire an equivalent paid professional to replace the family carer. The approach adopted in this study is most consistent with economic theory, but it does underestimate the costs to the exchequer if existing carers were unavailable or decided to provide less care and therefore had to be replaced in full or in part by paid caregivers. The replacement cost method, in which the hourly wage rate of a health care assistant is applied to value caregiving hours in the sensitivity analysis, highlighted the significant implications for costs of adopting such an approach – almost doubling overall costs.

While not without its limitations, this study has highlighted the significant costs associated with dementia in Ireland. In addition, it has shown the very heavy burden that falls on the family caregivers of people living with dementia in the community. Due to the impact of demographic ageing in the coming decades, particularly in relation to the increasing number of people with dementia, both family caregivers and the general health and social care system will come under increasing pressure to provide adequate levels of care. In such circumstances, it is hard to see how the system can cope unless dementia is made a national health priority (O'Shea, 2007) with all that implies for resource allocation and integrated care structures.





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# CHAPTER 4

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## COMMUNITY-BASED HEALTH SERVICES FOR PEOPLE WITH DEMENTIA

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I've told my children you needn't feel sorry for me. I still am who I want to be. What a shame it would be to live the rest of your life in regret. I'm not going to give up. I'm going to live until I die.

*from Keady and Harris, 2004*

”

# CHAPTER 4

## Community-based health services for people with dementia

### 4.1 Introduction

We have identified that there are about 42,000 people in Ireland currently living with dementia of whom about 26,000 live at home in the community supported by family caregivers and, if fortunate receiving appropriate statutory and voluntary services. We have also identified (Chapter 3) that the main economic cost of dementia care in Ireland is borne by the community and the main bulk of care in the community is provided free of charge by family caregivers, most of whom are adult children and spouses and many of whom are frail and older themselves. In Chapters 4 and 5 the key components of the current system of care for people with dementia living in the community are discussed within the framework of a “pathways” model or a notional journey through dementia. Drawing on Irish and international literature and an analysis of secondary data, this chapter reviews the current situation in Ireland in relation to primary care services, with particular regard to the role played by GPs and specialist services in dementia diagnosis and disclosure, the availability of support services immediately following diagnosis, and the role of community nursing services in the detection and management of dementia.

Dementia affects different people in different ways. It involves the fates of individuals along with the experiences and aspirations of family members and all those affected. If we include immediate family members and assume that each person’s experience of dementia will impact on four close family members, then at least 200,000 people in Ireland are currently affected. It is generally, however, the individual who first observes the signs and symptoms of dementia and it is the individual who, silently or otherwise, chooses to confront or deny the initial embarrassment, fears, and uncertainties that his/her invidious symptoms present. It is, therefore, the individual’s perspective that must inform our thinking, and it is the individual who must be placed at the centre stage and given priority in all policy development and in service planning.

At present a chasm exists between the individual’s experience of dementia and current policies and practices, since the voice of the individual experiencing the symptoms has seldom been listened to or included in the policy process. This phenomenon needs to change and the issue of what it means to have a dementia from the first person perspective must become a lot more visible in Irish society. The myths, ignorance and nihilism surrounding dementia also need to be challenged as the latter make it exceptionally difficult for the individual to come forward and for that person to live well with dementia.

The individual diagnosed must be afforded the opportunity to have a meaningful existence, one characterised by a good quality of life, despite the illness and the functional and cognitive losses associated. The dominant ideology about dementia including the various myths, stereotypes, negativity and taboos surrounding the illness must be tackled. We can never lose sight of the individual who must be afforded sufficient choice and the opportunity to live well with dementia and to be treated with dignity, kindness and respect. The public at large needs to be better educated about dementia so that there is more ownership of dementia at a community and societal level and a greater understanding of and sensitivity to the individual’s own unique experience.

### 4.2 Government policy and the particular challenges of dementia care

The stated aim of Irish government policy on dementia is to enable people with Alzheimer’s disease and related dementias to remain living at home for as long as possible (Working Party on Services for the Elderly, 1998). Best practice in primary and community care requires an early diagnosis of dementia and a careful assessment of individual needs and functioning. Best practice also necessitates a diverse range of flexible services which address the unique and chronic needs of the person with dementia and promote their quality of life.



In reviewing the research evidence for this report, a substantive body of published literature was found, demonstrating that caring for a person with dementia compared with other caring roles, places much greater demands and strain on family members (Bertrand et al., 2006; Ory et al., 1999; Pinquart and Sörensen, 2003; Zarit et al., 1999). The family caregiver of a person with dementia is much more likely to be providing 24 hour care, sometimes struggling to cope around the clock with distressing challenging behaviours such as repetitive questioning, sleep disturbance, dangerous, suspicious or accusatory behaviour; concerned about the safety needs of the person, suffering from physical exhaustion and experiencing considerable emotional and psychological strain (O'Shea, 2007). The family caregiver of a person with dementia is also more likely to be in poor physical health and on medication for his or her own health related problems (O'Shea, 2003). In a European research study reported some years back in the literature Irish family caregivers at follow up reported the highest level of strain compared with their counterparts in the UK, Finland, Norway and Lithuania (Gilliard and Hagen, 2004). There is also good evidence from the literature (Künemund and Rein, 1999) reflecting the fact that generous health and social care systems can reduce caregiver burden, and enhance family commitment to caring.

Begley's recent study of 17 persons with dementia and their care-partners demonstrated that the early information and support needs of people recently diagnosed were enormous and were often unmet (Begley, 2009); a curious finding given that her study's participants had each been diagnosed in an urban hospital and were well connected into consultant-led integrated care systems. Hasting's study showed that family caregivers were under considerable financial strain and that dementia remained hugely stigmatising ("nobody wants to hear about it") in Irish society (Hastings, 2009). Recent research results show that there is an absence of an adequate skill-base in relation to dementia assessment in Intellectual Disability services (De Siún and Manning, 2010; McCarron et al., 2011).

## 4.3 Primary care

### 4.3.1 The benefits of early diagnosis

There is now convincing evidence that early accurate diagnosis of dementia is critical to best practice in dementia care and yet across most European countries, including Ireland, dementia remains largely invisible and under-diagnosed (Bamford et al., 2004; Carpenter and Dave, 2004; Leifer, 2003; Lopponen et al., 2003; Wilkins et al., 2007) both in the community, in hospital settings and in nursing homes. Anyone worried about their health and experiencing symptoms of an illness has a right to a diagnosis. In this regard, people with dementia are no exception. Each of the National Dementia Strategies reviewed for this report has highlighted early diagnosis as a core area for health care service reform. Yet, the vast majority of people with dementia in Ireland have never received such a diagnosis.

For example, the National Dementia Strategy in England has a clear vision to 'make early diagnosis and treatment the rule rather than the exception' (Department of Health, 2009: 21). A core aim of England's National Dementia Strategy is to ensure that effective services for early diagnosis and intervention are available nationwide, for all, including younger people and those with an intellectual disability. The strategies in Scotland, the Netherlands, Norway and Australia are particularly useful for Ireland because of their emphasis on developing the capacity of GPs to assess and diagnose people with dementia.

There is consensus in the literature that GPs play a pivotal role in the accurate and early diagnosis of dementia (O'Shea and Reilly, 1999) and that important benefits can accrue to both the individual, the family caregiver, and to society at large from accurate early diagnosis and intervention (Bamford et al., 2004; Carpenter and Dave, 2004; Leifer, 2003).<sup>23</sup> The benefits to the individual include the fact that he/she may still be able to actively participate in

<sup>23</sup> It needs to be remembered that early diagnosis can in a minority of cases result in the identification of treatable causes of dementia such as delirium or nutritional deficiencies and can help distinguish dementia from other conditions which can mask dementia such as depression.

short and long-term care planning and engage in decision-making about important issues including drug treatments, legal and financial affair management, and service options.

In some instances, getting a diagnosis may be psychologically beneficial since the person experiencing the symptoms may still have insight and may be anxious and under pressure by spouse or relatives for what is perceived by them as forgetful, unreasonable, inappropriate or decidedly “odd” behaviour. In about one third of cases, drug therapy may help to delay the progression of the disease (Overschott and Burns, 2005). Informing and educating people with dementia about the condition can enable them and their caregivers to adjust and adapt (Connell et al., 2004; Derksen et al., 2006). These benefits in turn may improve the individual’s quality of life and reduce caregiver stress. Furthermore, and at a societal level, timely diagnosis can reduce healthcare expenditure by delaying nursing home admission (Leifer, 2003).

### 4.3.2 The need for databases in primary care

Despite GPs themselves acknowledging the benefits of early diagnosis (Cahill, Clarke et al, 2008), in keeping with countries such as the UK, the USA and Australia (Fortinsky, 2008), diagnostic practices in Ireland are less than optimum and the majority of people with dementia remain hidden in our society and never get diagnosed. Likewise, many Irish people with early onset dementia and people with an Intellectual Disability are either misdiagnosed or their dementia remains undetected (Haase, 2005; McCarron et al., 2011: 120). There is no mandatory requirement that Irish GPs keep a register of patients known to have a diagnosis of dementia, although efforts are currently underway by the HSE that such a policy is adopted. This is in contrast with the UK, Northern Ireland and Scotland, where primary care databases on dementia are kept. Nor is there any financial incentive in Ireland to detect and diagnose dementia since by far the majority of older people presenting with the condition are medical card holders for whom GPs receive a once-off annual capitation fee. Other European countries are experimenting by including pay-for-performance elements in their systems of remunerating GPs, whereby GPs are afforded financial incentives for chronic disease management (Brick et al., 2010).

Thus, the approach taken in Ireland compares unfavourably with other countries like England and Scotland where financial incentives exist and where GPs are paid according to services provided (Koch and Iliffe, 2010). In Ireland, making a diagnosis of dementia is often a slow unwieldy process, unnecessarily lengthened by GPs’ lack of immediate access to Memory Clinics and other diagnostic services and lack of prompt feedback to GPs from more specialist services. Our review would lead us to surmise that there is a need to create more appropriate resources and incentives to support GPs in the diagnosis of dementia. There is a need to support the development of shared care protocols between GPs and secondary care services and to support GPs in the ongoing management of people with dementia in the community. There is a need for clear accessible pathways to diagnosis. In Scotland, the concern about the under-diagnosis of dementia by GPs has led National Health Service (NHS) Boards there to establish agreed targets for improvements in early diagnosis and for service response to people with dementia. As a result of this planned Strategy, between March 2009 and February 2010 a net increase of 3,290 patients with dementia was registered by GPs.

### 4.3.3 The need for clinical guidelines on diagnosis

As stated, in Ireland there is no national dataset on actual numbers of people diagnosed with dementia by GPs. There is also an absence of national guidelines available to assist Irish GPs diagnose. This is in contrast to the UK where, under the NHS, clinical guidelines exist.<sup>24</sup> One consequence of all of this is that we do not have up-to-date information on how many of the approximately 26,000 people estimated to be living at home with dementia in Ireland

<sup>24</sup> National Institute of Health and Clinical Excellence (NICE) and Social Care Institute of Excellence (SCIE).

have received a clinical diagnosis. Nor do we have accurate and reliable data on numbers of people with Down syndrome in Ireland who have an Alzheimer's type dementia. We have no up-to-date information on current practices adopted by Irish GPs in relation to dementia diagnosis and disclosure. Based on prior research (Cahill et al., 2006), we know that Irish GPs, like their European counterparts, experience much difficulty diagnosing dementia, encounter structural and ideological barriers (including stigma) and blame themselves for the late presentation of dementia. We also know that a very large proportion (83%) of the 600 GPs surveyed in this study would welcome dementia-specific training. Some seven years later, there is little dementia-specific training available to GPs, but efforts are currently being made to change this. For example, the Irish College of General Practitioners (ICGP) has developed a distance learning module on Alzheimer's disease for GPs, which appeared in the April 2011 edition of its magazine, *Forum* (Swanwick, 2011).

#### 4.3.4 Making and disclosing a diagnosis

In the absence of a definitive test, diagnosing dementia requires time, skills, resources and determination. It is noted that it occurs against a backdrop of medical uncertainty. Many GPs express concern about the dilemmas encountered particularly in relation to differentiating normal ageing from the signs and symptoms of dementia and of imparting "bad news" to their patients (Cahill, Clark et al, 2008; Koch and Iliffe, 2010). It must also be remembered that the individual may be complicit in concealing a dementia, as symptomatic patients may not actively seek out help for their memory and cognitive problems for a variety of reasons including fear and stigma. Therefore, a proactive rather than reactive approach is needed; one which it is argued GPs are not prone to using (Iliffe et al., 2005).

It has been suggested that this medical uncertainty and reluctance to diagnose can be minimised by the dissemination and use of clinical practice guidelines for GPs and specialists (Fortinsky, 2008), and by educational programmes designed to tackle "therapeutic nihilism", increase clinical knowledge and bring about attitudinal change. Koch and Iliffe (2010) suggest that rather than simply increasing clinical knowledge, educational interventions for GPs should ideally be attitudinal, focusing on GP's perceptions of their suitability and ability to diagnose and the value of doing so in a timely way. Downs and her colleagues demonstrated the effectiveness of decision support software in GPs surgeries and of practice based workshops for improving detection rates of dementia in primary care (Downs et al., 2006).

#### 4.3.5 Communicating news of a diagnosis

Once a diagnosis is made, how news of dementia is conveyed to the individual and the support offered by the GP then and during the entire (sometimes) long duration of the condition greatly influences how people cope with the illness. The majority of people with mild dementia wish to know their diagnosis (Pinner and Bouman, 2003; De Lepeleire et al., 2004) and, in line with current practice guidance, it is generally recommended that all GPs discuss the diagnosis with the person with dementia, unless there are clear reasons not to do so. However, international research shows that there is wide variation in GPs' disclosure practices (Bamford et al., 2004; Carpenter and Dave, 2004)

The literature generally points to a reluctance on the part of many GPs to share a diagnosis with their patients (Iliffe et al., 2005) and Irish disclosure rates to patients rank poorly with disclosure practices adopted in countries such as the UK and Norway (Cahill et al., 2006). It has been noted that when disclosing a diagnosis, some GPs tend to avoid using overt terms and instead speak covertly using euphemisms such as 'memory problems' or 'confusion' (Downs et al., 2002; Lecouturier et al., 2008; Moore, 2010; Woods et al., 2003). There is also some evidence that GPs spend very limited time on elaborating or explaining the diagnosis to their patients (Lecouturier et al., 2008). Disclosure patterns in dementia today have been compared with the more covert approaches used to disclose cancer to terminally ill patients in the past.

Some experts suggest that diagnosis would best be achieved through a two-stage process with more integrated use of secondary services. First, the GP in detecting cognitive impairment and loss of function might suspect dementia, but the actual diagnosis, particularly differential diagnosis, would be confirmed by specialists such as Geriatricians, Old Age Psychiatrists or Neurologists (Waldemar et al., 2007). Whilst we have no data for Ireland in relation to who makes the diagnosis and where the diagnosis of dementia is made, the important diagnostic role played by Geriatricians and Old Age Psychiatrists in Ireland in this context and their ongoing role in the care and support of people with dementia is critical.

Quick and easy access to specialist services facilitates early detection and care of people with dementia, whereas lack of support from and poor communication with secondary specialist care are impediments to good quality care (Koch and Iliffe, 2010; Yaffe et al., 2008). Even GPs professing to have good knowledge of dementia desire more specialist input, which may be an indication of the complexity of dementia diagnosis and care and/or that GPs are responding to patients' or families' need for input from more 'authoritative' clinicians (Yaffe et al., 2008). One of the complaints voiced by GPs about specialist services was that waiting times for secondary services were often long (Cahill, Clark et al., 2008). It has also been noted that there is a need for more rapid access to Memory Clinics and for more integrated systems of communication to occur between staff in acute hospital services (including accident and emergency departments), Memory Clinics and GPs. While Ireland has witnessed a significant increase in the numbers of both Geriatricians and Old Age Psychiatrists employed by the HSE (there are currently 70 Geriatricians and 30 Old Age Psychiatrists, compared with 30 Geriatricians and 5 Old Age Psychiatrists in 1999 (Swanwick, 1999), there are still insufficient numbers of these specialists to cater for the growing demands of our burgeoning ageing population. In particular, significant gaps have been identified in some community care areas such as Kildare, Wicklow, Cork and Roscommon (Feeney, 2009).

### 4.3.6 The role of Memory Clinics in dementia diagnosis

The English National Dementia Strategy and the French National Plan for Alzheimer and related diseases in particular have highlighted the role that Memory clinics play in the early diagnosis of dementia. In England, the Department of Health, as part of its Dementia Strategy, has expanded the number of Memory Clinics available to the public across the country and hopes over the next two years to ensure that Memory Clinics are available in every town and city across the country. Our review has pointed to the fact that Memory Clinics in Ireland are not available in every HSE area (there are now 12 across the country) and there is also considerable variability across these clinics in relation to the type of service on offer and how such services are resourced and financed. Some Memory Clinics are well-resourced and employ a full complement of allied health professionals whilst others are more stand-alone. A few employ their own Neuropsychologists, whilst most do not have immediate access to this specialist service. Some Memory Clinics offer daily services whilst others are bi-monthly. The Memory Works clinic at Dublin City University reflects a unique model of service delivery in Ireland as its focus is not diagnostic but rather on screening, assessment, psychological support services and specialist referral.

Most of the Memory Clinics in Ireland, including St Joseph's in Clonsilla,<sup>25</sup> are based in Dublin, while some parts of the country including Kerry, Donegal, North Tipperary, Wicklow and the West of Ireland has been very poorly served with no Memory Clinics available.<sup>26</sup> The West of Ireland, and the counties of Kerry and Donegal, for example, each of which according to our estimates (see Table 2.6, Chapter 2) support in or around 2,000 older people with dementia have no Memory Clinic facilities whatsoever. This is despite emerging evidence that these specialist services are highly valued by both patients and family caregivers because of the opportunities they afford for in-depth discussion about the illness and prognosis (Cahill, Gibb et al., 2008).

<sup>25</sup> There are two Memory Clinics in Ireland dedicated to people with an Intellectual Disability, one of which is run by the Daughters of Charity.

<sup>26</sup> A Memory Clinic is planned for University Hospital, Galway, but has not as yet been set up.

Whilst a consensus exists in the literature that the diagnosis of dementia is the responsibility of GPs, it is noted from the review work undertaken for this report that the Welsh, French and the English Strategies/Plans emphasise the importance of specialist memory clinic services for the assessment and diagnosis of dementia with a complementary role for GPs and other secondary services. Having carefully reviewed this body of literature, it would seem that a multi-pronged approach to the detection of dementia, with diagnosis occurring both in primary, secondary care services and at Memory Clinics is the preferred approach. This is consistent with the recommendation made in *A Vision for Change* that 'primary health care teams should play a major role in assessment and screening for mental illness (including dementia) in older people and should work in a co-ordinated and integrated manner with the specialist team to provide high quality care, particularly care that is provided at home' (Government of Ireland, 2006: 121).

Given the stigma of dementia in Ireland (Nolan et al., 2006), the Welsh model is particularly interesting in that it emphasises a two-tiered system of specialist service delivery including: (i) memory assessment services – an approach which may be less stigmatising as the focus is more on “minding your memory” and includes providing services to the worried well; and (ii) memory clinics, where the focus is on diagnosis and treatments. In Wales, the aim is to increase the diagnostic capacity of Memory Clinics so as to diagnose all of those referred in a local area within an acceptable time limit as per waiting time target. Whilst, as mentioned in Chapter 1, both genetic and environmental factors determine who gets a dementia, certain dementias are largely avoidable or preventable and an important benefit of Memory Assessment clinics is that they enable people who have no organic pathology but nonetheless are worried about their memory (the worried well) to be educated about lifestyle issues and about ways of avoiding getting a dementia.

### 4.3.7 Irish people's experience of getting a diagnosis

We have limited knowledge or data available in Ireland on people's experience of getting a diagnosis of dementia. However, anecdotal evidence suggests that like in other countries experiences are not always that positive (Reminiscence Group, Oct 2011). In Ireland, the 21 participants in the National Dementia Summit, 2011 (ASI, 2011), two of whom had mild/moderate dementia, highlighted the fact that people with suspected dementia often experience difficulty in getting a referral to a specialist; there were often long delays in accessing specialists and marked differences in waiting times between public and private secondary services. For younger people with dementia, the diagnostic experience tended to be even more difficult, according to these participants. It was also highlighted during the same Summit that Irish people living outside metropolitan areas had particular difficulties in accessing secondary services. The findings from this Dementia Summit echo earlier research findings highlighting some of the structural barriers GPs encounter attempting to diagnose (Cahill, Clark et al., 2008).

**Box 4.1** Approaches to diagnosis of dementia in other countries

- › Diagnosis at a primary and secondary care service level, as well as at Memory Clinics.
- › Proactive approach taken by GPs in dementia diagnosis.
- › Evidence-based, clinical guidelines on diagnosis.
- › Widening and deepening the knowledge and skill-base of GPs in the detection and diagnosis of dementia.
- › Resources and financial incentives in place to assist GPs diagnose and manage dementia.
- › Formal roles for Geriatricians and Old Age Psychiatrists to assist GPs in the early diagnosis and on-going support of people with dementia living in the community.
- › Memory Clinics and Memory Assessment services part of diagnostic infrastructure
- › Shared care protocols between primary care and secondary care services around diagnosis, referral, and intervention, in all geographical locations.
- › Dementia diagnostic services available for younger people and people with intellectual disability.
- › Emphasis on people with a dementia having a right to know their diagnosis should they so wish.
- › Evidence-based standard guidelines for GPs and other primary care health professionals on the disclosure of dementia.

## 4.4 Support services immediately following diagnosis

The previous section of this chapter highlighted the importance of developing effective primary and secondary services and Memory Clinics for the timely and accurate diagnosis of dementia. Getting a diagnosis, however, is only the first step in the individual's journey through dementia. Indeed, acquiring a diagnosis is sometimes said to expose a 'care gap', where people are left with a clinical diagnosis but with little to no useful support (Iliffe and Manthorpe, 2004). The experience of people recently diagnosed with dementia and their relatives are complex, as are their support needs. The individual may feel depressed, frightened, embarrassed or distressed and will generally need considerable emotional and practical support during this very difficult period. The person recently diagnosed, rather than being seen as the bearer of a ghastly disease, has feelings, rights and responsibilities and needs as far as possible to remain involved in decision-making about lifestyle choices.

Several people with dementia and their families who participated in the recent National Dementia Summit 2011 (ASI, 2011: 6) described how after getting the diagnosis, they felt they were 'in an abyss'. Many were unsure of where to seek support, who to contact regarding services and entitlements and where to go to acquire critical information. Begley's work confirmed these findings; she showed how some family caregivers in their quest for information had to resort to newspaper and magazine articles. In addition, Begley documented the emotional responses these people had to their diagnosis, including anxiety, frustration, a sense of sadness and anger, and guilt about becoming a burden on others (Begley, 2009). It is important to keep in mind that the inability to get information and to receive emotional support when it is first needed may dampen efforts to source information or support later. This may ultimately cause delays in securing services for a family member (Robinson et al., 2009). It is clear from the Irish research referred to here and the testimonies collected that there is a need for more adequate timely post-diagnostic support services for people with dementia and their families.

The following section reviews the early support services available to people with dementia and their carers in Ireland and in other countries. As mentioned in the introduction of this chapter, the onset of dementia generates a great deal of concern for all those involved. There are concerns for the individual who gradually realises that a deterioration is occurring, for those who nominate to become caregivers and for significant others. The misfortune for all those involved is attempting to make sense of the symptoms and behaviour that can no longer be thought of as rational and systematic. While there is no consensus about what constitutes a good model for early support service for those newly diagnosed with dementia and their carers, our review suggests that: (i) information services; and (ii) counselling and emotional supports are often required. That said it needs to be remembered that there are few proven and internationally accepted evidence-based psychosocial interventions for people with early stage dementia living in the community (Moniz-Cook and Manthrope, 2009).<sup>27</sup> The next section in this chapter addresses these important areas.

### 4.4.1 Information and support services

Different countries have taken different approaches to developing post-diagnostic supports for people with dementia and their families. In England, Wales and Northern Ireland, information-giving is treated separately from other post-diagnostic supports. For example, one of the key objectives of England's National Dementia Strategy is the 'provision of good quality information on the illness and on the services available for those diagnosed with dementia and their carers – both at diagnosis and throughout the course of their care'. In Northern Ireland, the role of GPs, memory clinics, other community based services and the voluntary sector in providing good quality information is emphasised. One of the actions recommended is for the Northern Ireland Dementia Services Development Centre to develop an information pack for GPs. In Australia, a key priority of its Framework of Action on Dementia is to establish links between specialist dementia information services and other information services.

Little is known about how people with dementia and their family caregivers in Ireland access information about dementia or, indeed, how they deal with the transient and sometimes invidious symptoms of early-stage dementia. The participants in the recent National Dementia Summit pointed to the need for timely information and claimed that it took them considerable time, energy and frustration to get the information they required (ASI, 2011). Despite these findings, we are aware that there is an emerging body of information-kits and booklets being produced by organisations such as the Alzheimer Society of Ireland (ASI), The Living with Dementia Programme (LiD) and the Dementia Services Information and Development Centre (DSIDC). Whilst we know that the information needs of people with dementia are not entirely the same as the needs of their relatives (Cantley and Smith, 2007), much of this written information is targeting almost exclusively the family caregiver or the health service professional and there is a deficit of materials designed to inform and advise the person with dementia. There is also some additional relevant literature on end-of-life and dementia including leaflets being produced through the Irish Hospice Foundation (IHF) and Clare Mental Health Services for Older People. In addition to this written information, the ASI operates a national helpline and has two drop-in centres in Dublin dedicated to providing information to people affected by dementia.

A key difficulty is that a large majority of those in quest of post-diagnostic information are unaware how and where to access it. In this context, younger people with dementia appear to be most disadvantaged and claim that there is a dearth of appropriate information available to them (ASI, 2011). People with dementia living in rural areas may be spatially disadvantaged, given the preponderance of information and support services in urban areas. Not everyone has access to the internet and because Ireland is a small country and dementia remains stigmatising, many people may be disinclined to seek out information from organisations such as the ASI and the DSIDC for fear of labelling. Ideally, people need information in small amounts and the timing of when this information is received is considered very important (MacConville, 2011). Wald et al. (2003) found that most carers wished to have written information and valued the provision of information from independent sources. Their work also showed that families welcomed a staged approach to information, thereby allowing knowledge about the condition to be interpreted in an incremental way.

<sup>27</sup> Although one Dutch study has recently shown significant benefits accrued by both people with dementia and their family caregivers through introducing a carefully designed domiciliary-based 8 week occupational therapy programme (Graff et al., 2006; 2007).

The information needs of particular vulnerable groups such as young people with dementia and those with an intellectual disability and dementia are likely to be different from those of the majority population and may require specifically tailored approaches. In this context, in Ireland the Quality Dementia Care Standards developed for the Daughters of Charity services to support persons with an intellectual disability have helped to ensure that the needs of this particularly vulnerable group of people are addressed (McCarron and Reilly, 2010). Another useful example of good practice comes from the British Institute of Learning Disabilities (BILD) ([www.bild.org.uk](http://www.bild.org.uk)), which has developed a range of books/booklets about dementia for people with an intellectual disability. For example, *About Dementia: For People with Learning Disabilities* is a booklet in large print text for more able people with learning disabilities, which describes dementia in easy-to-understand language and provides answers to commonly asked questions. *About My Friend: For Friends of People with Down's Syndrome and Dementia* is an illustrated booklet which describes the dementia process and helps people with a learning disability understand what happens when a friend gets dementia. It uses large print text and is a very practical, easy to follow booklet.

Another very useful document containing a check-list on the type of information needs people with dementia and their families have is the NICE-SCIE guidelines (NCCMH, 2007). These guidelines stipulate that service providers should offer people with dementia and their families (unless they specifically ask not to be advised) information in written format about: (i) the signs and symptoms of dementia; (ii) its course and prognosis; (iii) treatments; (iv) local care and support services; (v) support groups; (vi) sources of financial and legal advice, and advocacy; (vii) medico-legal issues, including driving; and (viii) local information sources, including libraries and voluntary organisations. Regrettably, Ireland does not have similar guidelines.

#### 4.4.2 Counselling, rehabilitation and emotional support

A second community support service identified as being very helpful to people immediately post diagnosis is that of counselling and ongoing emotional and psychological support (Keady, Clarke and Page, 2007; Moniz-Cook et al., 2009). This service can help those recently diagnosed come to terms with the diagnosis, deal with the uncertainties associated, and adjust to the physical and psychological difficulties the condition presents. Offering such support at an early stage may also help, in the short-term at least, to maintain functioning and reduce disability. People with early stage dementia have many retained abilities and to some extent are capable of new learning and of changing their behaviour (Clare, 2004). Early support including cognitive rehabilitation, a more labour intensive service, may also prevent the development of 'excess' or unnecessary disability (Clare, 2011).

Post-diagnostic counselling aims to encourage people with dementia to use coping strategies to enable them "take on their diagnosis" and "work it through", emphasising the goal of "life beyond diagnosis" (Keady, Clarke and Page, 2007). In the UK and elsewhere, services aimed at post-diagnostic counselling constitute an area of early supports for people with dementia and their families that are growing in prominence (Keady, Clarke and Page, 2007). In particular, the unusual, troubling and challenging circumstances of people affected by early-onset dementia (many of whom are still in the workforce and may still have young financially dependent children) lend themselves especially to this type of post-diagnostic service.

Whilst Moniz-Cook et al. (2009) highlight the important role Memory Clinics have to play in the provision of such post-diagnostic counselling, the latter can also be undertaken by a range of health care professionals including GPs, public health nurses (PHNs) and Community Mental Health Nurses provided they are up-skilled in dementia care. Practice nurses also play a critical role in educating newly diagnosed people and their family members about coping strategies and maintaining independence. However, in Ireland post-diagnostic counselling is not usually offered to people immediately after diagnosis (Begley, 2009).



In the UK, Dementia Advisors have been appointed (across 22 nationwide locations) whose remit is to help people with dementia and their families navigate the care and support system throughout their illness and help to ensure easy access to care, support and advice.<sup>28</sup> In France, a national dementia help-line which caters for people's information needs and which co-ordinates care at a district level is a new service being piloted under the French Alzheimer and related diseases Plan. A national telephone line is available which links people with dementia and their carers to their nearest local agency where all information about services in a given district is available through a care co-ordinator.

All of these findings have reinforced our view that in Ireland there is an absence of focus on support services around the time of, and immediately following diagnosis. Consequently, there is an urgent need to develop local, well-coordinated support services that would assist people and their families to cope with the choices and dilemmas confronting them at this often distressing and challenging time. Our view, therefore, is that once a diagnosis is made protocols need to be put in place to ensure that families get the support they need during this critical phase. Best practice would involve families first being referred to a HSE service co-ordinator in the relevant community care area and onwards to a Case Manager assigned to work with the person with dementia and their family. An effective integrated system of care requires that there are clear, coordinated and definite routes into a range of community services (Øvretveit, 1993) and the Case Manager would draw on the full range of community care services and be allocated a budget to purchase appropriate services.

#### Box 4.2 International best practice on post-diagnostic supports

- Comprehensive information on dementia available in a wide variety of formats to meet the diverse needs of people with dementia and their carers throughout the different stages of dementia.
- Information provided in a staged approach and over a number of routine visits.
- Post-diagnostic services available at a community level to address the immediate social, psychological and emotional needs of people recently diagnosed with dementia.

## 4.5 Community nursing services

A significant proportion of this chapter has so far been devoted to discussing the critical role played by GPs in the diagnosis and disclosure of dementia as we consider this area very important for an emerging Strategy for dementia in Ireland. We have also identified the relevant early support services needed by people with dementia and their family members immediately following early diagnosis. However, the care of people with dementia is an ongoing process and will often continue for many years after the initial diagnosis is made, during which time ongoing GP involvement and input from a whole range of service providers including nurses, social workers, occupational therapists and home support staff is required. The next section of this chapter will address the role registered nurses, including: (i) practice nurses; (ii) public health nurses; and (iii) community mental health nurses, play in the care of people with dementia. Where relevant, examples of good practice from national and international literature are drawn on.

### 4.5.1 Practice nurses

There are currently around 1,700 practice nurses in Ireland, about one third of whom (579) are members<sup>29</sup> of the Irish Practice Nurses Association.<sup>30</sup> Of these, 211 Practice Nurses are accredited as Clinical Nurse Specialists (CNS), two

<sup>28</sup> A randomised controlled trial to assess the impact that dementia advisors have on the quality of life of people with dementia is currently underway at Kings College London.

<sup>29</sup> Those on the Active Register of An Bord Altranais in the RGN or RPHN divisions who are currently working as a Practice Nurse alongside a GP in the Republic of Ireland are eligible for membership of the Irish Practice Nurses Association.

<sup>30</sup> A professional membership association of practice nurses in Ireland.

have been accredited as Advanced Nurse Practitioners (ANP) in Primary Care, and nine have begun nurse prescribing programmes. Six are now Registered Nurse Prescribers. Within the HSE, there are currently seven Professional Development Co-ordinators for Practice Nurses.

Practice nurses play a critical role in the assessment and support of people with dementia and their family members in other countries. For example, two recent Australian studies have highlighted the important role played by practice nurses in dementia assessment, medication control and behavioural management, and in referring families to other community services (DCRC, 2007; Buck, 2008). Likewise, in Australia, practice nurses on aged care assessment teams are integrally involved in dementia diagnosis and management. Despite our ageing population and the parallel growth in numbers of people with dementia living in the community, there is little information available in Ireland on the role that practice nurses play in dementia assessment and support in this country. The risk of dementia may be reduced if one's general health is protected by not smoking, having a healthy diet, exercising regularly, drinking moderate amounts of alcohol, and generally protecting the head from serious injury (Farrow, 2010; Kivipelto et al., 2005; Ott et al., 1998; Ott et al., 1999; Peila et al., 2002; Ruitenberg et al., 2002). Practice nurses have a key role to play in helping to educate people about the risk factors for dementia and about lifestyle choices which can be adopted to minimise the risk of developing a dementia across all of these areas. Practice nurses also have a key role to play in helping to recognise and detect dementia in high risk patient groups including those with diabetes, alcohol dependency, coronary heart disease and high blood pressure.

### 4.5.2 Public health nurses

Despite earlier calls for the more active involvement of public health nurses in the assessment and screening of dementia in the community and in the ongoing support of families living with a relative with dementia (O'Shea and O'Reilly, 1999), no reliable information to date is available in Ireland on the role public health nurses play in dementia care. This is despite the fact that useful data is emerging in Ireland on their role in the care of older people in general in the community. For example, we know that in Ireland about 13% of people over 65 years of age avail of public health nursing services (McGee et al., 2005) and that there is a positive correlation between age and use of public health nursing services with almost a quarter of people over the aged of 80 availing of this service (Normand et al., 2011). We also know that in Ireland in 2008, there were 2,439 public health nurses registered with An Bord Altranais.

Apart from having a role in dementia screening and assessment, in many instances public health nurses are the gatekeepers to other community care services such as home help, meals on wheels, day care and other respite care. They liaise with family doctors (GPs), practice nurses, hospitals, hospices and other health service providers and organise and co-ordinate other services often considered vital to maintaining older people at home within geographical areas. One of the key difficulties in Ireland today is that there are no public health nurses with a dementia-specific remit and the workload of the public health nurse remains extremely diverse. She is the "Jack of all Trades" so to speak (NicPhilibin et al., 2010); expected to provide from the cradle to the grave a myriad of different professional services including post-operative care, medication management, dressings changing. The care of people with dementia living in the community often requires a very flexible approach with individually tailored responsive services; however, public health nurse services tend to be task-focused and because of time constraints, they lack flexibility of response to fluctuating daily needs (Department of Health, 2011a).

Begley's study, for example, of people recently diagnosed with dementia (N=17) demonstrated that, whilst about one third of the sample had received a visit from the public health nurse, only two had ongoing contact and several would have welcomed much more regular contact for reassurance and support (Begley, 2009). Many of the participants in this study seemed acutely aware of the excessive demands placed on public health nurses and seemed grateful for whatever little help they actually received. Another study cited in the literature showed that whilst there is an estimated 2,357 people with dementia in the Galway LHO area (see Chapter 2) only 229 people with dementia (less than 10%) were known to public health nurses at the time this research took place (Kelly and Moran, nd). This same

study showed that most referrals of people with dementia to public health nurses were from family members and not from GPs. Families were often at a crisis when seeking support and public health nurses were not always able to provide the necessary intervention to allow the person with dementia to be cared for at home. It is likely that only a fraction of people with dementia in Ireland are known to public health nurses and that the service as it currently operates is not sufficiently flexible to meet the complex, chronic and fluctuating needs of people with a moderate to advanced dementia.

Records are currently not being kept on the number of Irish people with dementia who avail of public health nursing services. This situation is likely to improve in the not so distant future, as the HSE is currently in the process of introducing 'elderly registers' into each LHO which will include accurate diagnostic information on all clients. Obviously, the register will only be as good as the diagnostic information provided in advance by GPs, Secondary Services and Memory Clinics. However, the register could conceivably shed light on future numbers of people with dementia utilising public health nursing services.

### 4.5.3 Mental health nurse and old age psychiatry services

A third and more specialist type of nursing services available to people with dementia living in the community is that delivered under the auspices of community mental health services or Old Age Psychiatry Teams of which in 2009 the HSE had accumulated data on 22 such teams<sup>31</sup> (Feeney, 2009). *A Vision for Change* (Government of Ireland, 2006) highlighted the absence of mental health services for older people in many catchment areas and recommended that there should be a total of 30 dedicated Mental Health Services for Older People teams in Ireland.

Like Memory Clinics, Old Age Psychiatry team composition varies considerably across different geographical areas, and again the incomplete multidisciplinary representation on such teams was highlighted in *A Vision for Change*. Each Old Age Psychiatry Team employs at least two and in many cases three or more Community Mental Health Nurses/Clinical Nurse Specialists. Dementia can sometimes account for a very significant proportion of the workload of these nurses. Not infrequently they are involved in helping family members cope with complex day-to-day dilemmas confronting them because dementia, including coping with challenging behaviours such as paranoia, delusions, hallucinations, and aggression or with clinical issues including medication management, or in more extreme cases, organising emergency respite and long-term care.

The only Irish research conducted on the community mental health nursing services and dementia found that in rural areas 50% of their caseload were with people diagnosed with dementia (Farrell et al., 2007). Unlike countries such as the UK where community mental health nurses have a dementia-specific remit (e.g. the Admiral nurse in England) there are, as far as we are aware, only two community mental health nurses with a dementia-specific remit in Ireland. The development of specialist and advanced practice roles in nursing in Ireland is part of the ongoing strategic development of the health service as a whole, and, according to Farrell et al. (2007), the advent and expansion of community mental health nursing services have been critical to the improvement and expansion of services for people with dementia in Ireland. Supporting the ongoing development of the service through a greater focus on dementia-specific skills sets within teams is important and would reflect current international practice.

### 4.5.4 Challenges facing community nurses

Research conducted with community mental health nurses has highlighted the major challenges they confront caring for a person with dementia (Farrell et al., 2007), and many of these concerns were re-echoed in later research by practice nurses and public health nurses (De Siún and Manning, 2010). One challenge is the lack of much needed

<sup>31</sup> Whilst the HSE is maintaining a database on Old Age Psychiatry services regrettably no information or records are being kept on utilisation of these services by people with dementia.

76 services including home help, respite facilities, dementia-specific day care services and out-of-hours services. Another is attempting to support people with young-onset dementia and their families for whom there appears to be very few resources available. A third challenge is the reluctance of some people particularly in the early stages of dementia to accept support. Nurses identified the difficulties that people with dementia and their families faced in coming to terms with a diagnosis of dementia and pointed out that a lot of their work centres around counselling (De Siún and Manning, 2010). Safety was a big issue and community mental health nurses had concerns about leaving vulnerable and cognitively impaired people at home alone at night and at weekends when no services were available. Other concerns centred round delays of up to one year for non-urgent referrals; absence of relevant support and back up services available, particularly in relation to social work and occupational therapy access. Other challenges facing community mental health nurses employed in rural areas included poor transport, an absence of family carers, poor day care provision, isolation, bad roads, and overall poor access to services (Farrell et al., 2007). These findings lead us to conclude that community-based nurses are under-resourced and as such cannot do their job effectively.

### 4.5.5 Education and training of nurses working in the community

Like other health and social care staff in contact with people living at home with dementia, practice nurses, public health nurses and community mental health nurses need training in dementia care. Irish research has shown that the vast majority (83%) of nurses, for whom dementia comprises a significant part of their workload, lack specialist knowledge and have not received training in dementia care, with no significant difference between nursing managers and clinical nursing staff. This research has shown that in particular public health nurses and practice nurses (as compared with community mental health nurses and nurses based in nursing homes) were less likely to have received specialist training (Farrell et al., 2007; De Siún and Manning, 2010).

This lack of specialist knowledge in dementia care among nurses working in the community is a phenomenon likely to change given the myriad of training programmes available around Ireland by specialists including staff at the DSIDC (who deliver a nation-wide training programme along with extra-mural classes), private consultant trainers, SONAS aPc and given the recent launch of the National Dementia Education Project (NDEP), a training programme being rolled out through HSE Centres for Nurse Education as well as non-HSE agencies in most parts of the country. But training needs to happen quickly and in a consistent manner across all geographical areas. Training also needs to be multidisciplinary with training budgets made available on an equal footing to all staff involved in the care of people with dementia (irrespective of occupational group). There should be recognition within organisations that caring for people with dementia is highly skilled work that is emotionally and physically demanding and requires ongoing specialist training (Brooker, 2007).

## 4.6 Summary and conclusion

Based on a perusal of the international and national literature the main priorities for optimal primary and community care provision for people with dementia in Ireland are summarised below. Of course we are aware that current public expenditure controls make it very difficult to achieve optimal provision, but some of the additional spending can be met from redistribution within existing health budgets.

- › Early diagnosis (ideally differential diagnosis) with access to quality information on the disease including the dementia sub-type and prognosis, and on treatments (pharmacological and non-pharmacological) and support services;
- › Development of professional needs assessment and individual care plans, which are regularly updated;
- › Availability and accessibility to wide range of community support services which are flexible, individualised (addressing the changing needs of the individual) and provide where necessary around the clock support to both the individual diagnosed and the primary caregiver;
- › Continuity of care for the duration of the condition with the appointment of a “key worker” or Case Manager;
- › Education and practical skills training for health and social care professionals;
- › Education and public information about dementia at local and national levels;
- › Education about the medico-legal aspects of dementia including driving, financial management and Enduring Powers of Attorney;
- › Advocacy at a local and national level;
- › Realistic and adequate financial support for family caregivers.

Diagnosis is critical to the initiation and development of appropriate pathways to care in dementia. In Ireland early diagnosis and sometimes any diagnosis is the exception rather than the rule. Even when the symptoms are obvious there may well be a reluctance to label someone with dementia because of negative attitudes and stigma. There may also be a false belief that nothing can be done. It is, therefore, critical that people with dementia get the services (diagnostic, information, community support services, residential and palliative care) they need when and where they need them and there is growing evidence from the Irish literature that people with dementia, including those with early onset Alzheimer’s disease and those with Down syndrome related Alzheimer’s disease, experience much difficulty accessing appropriate community care services (Hastings, 2009; Begley, 2009; Haase, 2005; Argyle et al., 2010).

Based on the literature review conducted for this report, our belief is that the best way to ensure that people get the services they need is to develop a system of case management for people with dementia and have available ‘dementia champions’ (be they Admiral nurses or dementia advisors as is the case in the UK or specialist dementia teams as is the case in the Netherlands, Norway and Sweden) to assist and support people in their journey through the disease trajectory. In the Netherlands, for example, case management improvement projects have been implemented in many parts of the country and the various forms of case management that exist are expected to meet certain minimum requirements. Studies there have shown people with dementia and informal carers benefit from case management (Ligthart, 2006; Groenewoud, *at al* 2008).

Dementia is an invidious progressive condition for which there is currently no cure and no clinical solution. There is also a lack of knowledge about dementia in our society in general and amongst health service professionals. Services offered are fragmented, poorly co-ordinated, inflexible and inequitable. In short, the service system is inadequate and, as shown in this chapter, critical links are often missing in the chain of services available to meet the complex needs of these vulnerable people. It is our view that appropriately designed and delivered services can play a major role in impacting positively on the lived experience of dementia.

The individual experiencing the symptoms of Alzheimer's disease along with family members confronting dementia need a key contact person whom they trust and who is knowledgeable about a whole range of pertinent dementia related issues: they need a designated contact person to co-ordinate the individual care plans of the person with an assured link to appropriate services and to navigate the complex care pathways and range of services. As stated in *An Action Plan on Dementia* (O'Shea and Reilly, 1999), a case management approach both for people with early-onset dementia and for older people with dementia could be accommodated within the existing framework of health and social services.



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# CHAPTER 5

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## COMMUNITY-BASED SOCIAL CARE SERVICES FOR PEOPLE WITH DEMENTIA

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I really need more care now for him. I haven't found care very easy to source ... you know everybody will say to you 'Oh it's there. You can easily get it' but I'm afraid ... I mean I was never looking for anything for nothing but I wanted ... somebody that ... is trustworthy because you are leaving your husband with somebody but I had to do all that myself.

*Family carer of person with dementia*

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# CHAPTER 5

## Community-based social care services for people with dementia

### 5.1 Introduction

The discussion in Chapter 4 centred round the core Irish health care services delivered through the HSE and utilised by people with dementia, including GP and community nursing services and more specialist professional health services including those offered by Geriatricians, Old Age Psychiatrists Neuropsychologists and Memory Clinics. However, dementia care, as mentioned earlier, often involves hard physical round the clock labour; cooking, cleaning, dressing, showering, feeding, vacuuming and sometimes have to scrub down walls and carpets after repeated episodes of incontinence. Accordingly, apart from health services, families dealing with dementia need vital non-medical interventions including Home Helps, Home Care Packages and Respite Care services in order to help them sustain the caregiving role. The individual's journey through dementia may be enormously enhanced or aggravated by the presence or absence of such critical personal and social care services. No two people with dementia are the same and good dementia care means meeting the individual where he/she is currently at, and introducing individually adapted services based on an in-depth understanding of the individual's medical history and his or her life story, biography, wishes and preferences. This chapter presents findings from the literature on social care and from our analysis of secondary data on community care services. This will be preceded by a brief discussion of some of the broader debates in the overseas dementia literature about service preferences and models for dementia service delivery.

### 5.2 Specialist versus generic community care services

One particularly important issue highlighted in this literature, and salient for Irish service planners and policymakers, is whether community care services should be dementia-specific or generic (Marshall, 1999). Some experts argue that because the needs of people with dementia are unique and chronic, they undoubtedly require more individualised specialist services and that specialist services are the preferred model in dementia care since the latter can delay placement and can better cater for the aggressive nature of some dementing conditions, (Tinker, McCreadie and Salvage, 1994). However, the counterargument is that specialist dementia services may lead to the segregation of people with dementia from society, adding to the stigma of dementia, leading to a reduction in the individual's quality of life (Stone, 2001).

Interestingly, in a study that formed part of the research evidence base for the National Dementia Strategy in England (Department of Health, 2009), Challis and his colleagues concluded that there is little real evidence pointing to the differential benefits of specialist home care services over more generic services and little evidence of a significant cost differential between the two types of service delivery (Challis et al., 2010). Curiously, in another UK based study, researchers found that with the exception of one key quality attribute (i.e. user centred practice) few differences in quality standards existed between specialist and non-specialist home care services (Venables et al., 2006). Challis et al. (2010) conclude that many of the key quality attributes may be provided by both generic and specialist home care services for people with dementia, albeit with different emphases.

Challis and his colleagues have also undertaken interesting work surveying family caregivers about service preferences in the context of domiciliary dementia care services (Challis et al., 2010). Their research shows that these informal caregivers expressed a strong preference for consistency in domiciliary care services and in having the same care worker visit throughout. Training was another important attribute of home care support highly valued by family caregivers who believed that the personal qualities of the home care worker were what mattered most. They also claimed that professional training needed to focus on non-verbal communication and that paid care staff needed a thorough understanding of the particular subtle demands made by a person with dementia. In their view, such workers should have sufficient knowledge to recognise the particular nuances of expression and unique features characteristic of dementia and, therefore, the ability to respond appropriately.



The study concluded that there are four main domains of quality that should underpin generic or specialist home care provision. These are: (i) individuality or person-centred practice; (ii) dementia-specific training for staff; (iii) continuity of care; and (iv) flexibility of response. Intensity of home care service provision, in terms of number of hours and frequency, was, according to Challis and his colleagues, also crucial for enabling people with dementia to remain at home (Challis et al., 2010). Regrettably in Ireland, we have no similar in-depth study of peoples' attitudes to dementia services to help inform service planning and shape the type of home and community care services these people most welcome. However, it is not unreasonable to assume that Irish views and attitudes to services are likely to be similar to those expressed by people involved in the UK survey. We also clearly need information from people with dementia about their own individual service preferences.

### 5.3 Supports for family caregivers

We have already mentioned that the vast majority of people with dementia in Ireland live at home and like in other Western countries, Irish family members, generally women, provide the main bulk of home and community care services. The 2006 Census showed that there were 160,917 carers<sup>32</sup> in Ireland, the majority of whom (62%) were women (CSO, 2007c). Whilst it is not possible to identify the exact numbers of these carers who provide regular unpaid personal care services and support to older people or people with dementia, it has been estimated that up to one third (i.e. 50,000) are currently looking after relatives with at least one symptom of dementia (O'Shea, 2000: 80). These caregivers by and large wish to be involved in the process of caring, including making decisions about the most useful services needed to help them in their caregiving roles. They are the experts and have an enormous amount to contribute as they are familiar with the past history and biography of the person they care for and many have become very resourceful in developing their own strategies for coping with the excessive demands of the dementia care role.

These 50,000 predominantly female caregivers, many of whom remain hidden in current Irish service structures, are, it has been argued, the lynchpin to the success of community care policies. Yet, many are under huge stress and are poorly supported by current social policy. The excessive strain of dementia care, as compared with other caregiving roles, has already been mentioned at the beginning of Chapter 4 (see page 65). Caring for a person with dementia is a complex, multi-skilled, demanding job involving long uninterrupted hours of sometimes hard physical work including lifting, washing, cleaning, monitoring and tending. Apart from being physically exhausting, it can be emotionally draining particularly in circumstances where close loving relationships become fractured and when the care-receiver no longer recognises a loved one.

It is also well documented that there are considerable opportunity costs associated with caregiving based on the plethora of services these carers provide. The money that family members are saving the Exchequer is also very considerable (see Chapter 3, page 53). Yet, the limited data we have on family caregivers suggests that relatively few receive State benefits or allowances. For example, the Carers' Allowance is restricted to those on low income living with and looking after people in need of full-time care and, as far we are aware, only a minority of family members caring for people with dementia satisfy the strict criteria to avail of this scheme. As noted by O'Shea and O'Reilly (1999), carers have repeatedly expressed a preference for direct payments for care not because they are materialistic but because they are keen to get some recognition from the state for the extremely valuable work that they do. Despite acknowledgement that the Carer's Allowance and Carer's Benefit Schemes are restrictive and, despite repeated calls for their reform including the elimination of means-testing, no significant reform has taken place. Reforming these schemes is now all the more difficult given the current severe budget constraints. However, it has been noted that funding systems in Ireland are currently biased in favour of providing in-patient care or residential care to older dependent people including those with dementia rather than on supporting family caregivers and giving them the recognition they deserve for the enormous hard physical work they undertake in their own homes and behind closed doors (O'Shea, 2000).

<sup>32</sup> In the Census of Population 2006, a carer is defined as a person aged 15 years and over providing regular unpaid personal help for a family member or friend with a long-term illness, health problem or disability. The number of people defined as carers under the Census of Population 2006 does not correlate with the number of people who qualify as carers under the Department of Social Protection's eligibility criteria for Carer's Allowance or Carer's Benefit.

## 5.4 Home care services

In Ireland, the Home Help Service and Home Care Support Schemes, otherwise known as Home Care Packages (HCP), are two important home care services developed to assist older people including those with dementia to remain in their own homes for as long as possible. These services are delivered either directly through the HSE, through community and voluntary organisations or through private providers, a rapidly growing unregulated industry currently burgeoning in Ireland and one carving out a niche in the provision of more flexible and round the clock services (Timonen et al., 2011). In relation to generic home help services, the focus of the HSE in recent years has been towards more professionalisation of the service and an emphasis on essential household duties and personal care; changes that are taking place in the context of competing demands, increasingly limited resources and efforts to improve quality of care and safety for older people. Dementia-specific home care services are also delivered through voluntary organisations such as the ASI whereby a trained dementia care worker is assigned to a person with dementia in the community for a designated number of hours per week.<sup>33</sup> In 2008, ASI reported that it provided 748,902 care hours to people with dementia (ASI, 2008). In supporting the person with dementia, it is also reasonable to assume that ASI care workers also provide some respite for family caregivers.

One of the resounding weaknesses of Irish home care services compared with those developed and delivered in other countries (such as the UK, Norway, Sweden, Denmark, France and Australia) is that these services are not underpinned by legislation and are not provided on a statutory basis. Accordingly, there is no onus on LHOs to provide services to people in need. On the demand side, lack of knowledge and confusion about entitlements to services combine to exacerbate supply-side inadequacies leading to significant gaps in home care service provision to people in need. There are also gross inequities across the country in relation to service availability with considerable variation in the type and amount of home care services available (PA Consulting, 2009).

Younger people with dementia (those aged less than 65), of whom we know from our calculations that there are at least 3,500, are known to be particularly disadvantaged (Haase, 2005) since services, even when they exist, were not originally designed for this age group. Likewise, those with very high dependency needs, such as people with moderate to advanced dementia are often disadvantaged, since not all HCP accept those who may require overnight care or 24 hour supervision. Indeed, there appears to be two emergent types of HCP, shorter-term (1-6 months for rehabilitation/convalescence) and longer-term (greater than one year for chronic needs). The latter, designed to maintain the individual with a diversity of needs at home, are likely to be more suitable for people with dementia and tend to be of a lower average weekly cost than shorter-term HCP (PA Consulting, 2009). In the absence of the required level of community support, people with dementia will be placed in long-term care prematurely. The absence of entitlement to home care services has been identified as a potential barrier to living at home and the main reason why some people with dementia can no longer live in the community (NESF, 2005; Timonen et al., 2011). The demand for statutory provision seems to be the only way to ensure that additional resources will be allocated to home care in light of competing demands, but it will be costly requiring additional resources or the redeployment of existing budgets.

It has long been argued (O'Shea and Reilly, 1999) that the introduction of legislation by way of a community care act and the provision of home care services on a statutory basis would permit a more co-ordinated response to the needs of people with dementia; would allow services to be more easily monitored and evaluated, and would alleviate regional disparities in service provision. Interestingly, in this context, several participants at the recent National Dementia Summit, claimed they had no sense of entitlement to such critical services (ASI, 2011). Whilst it is encouraging to

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<sup>33</sup> This service, whilst officially "home based", is designed to ensure that the Care Worker can support the person with dementia to become involved in other activities outside the home.

note that the Home Care Support Scheme has recently been evaluated and National Guidelines<sup>34</sup> (HSE, 2010) for their standardised implementation are due to be gradually implemented during 2011, it is disheartening to note that in this helpful 50 page document the specific challenges facing people with a dementia are all but overlooked.

### 5.4.1 Irish data on home care services

Like the UK (Knapp and Prince, 2007), Irish data on home care services (home help services and home care packages) for people with dementia is very limited. There is no mandatory requirement that service providers collect detailed data on the type of home care services they administer to people with a known or suspected dementia and accurate estimates of the percentage of these people using such services is not available. Therefore, the actual level of home care provision to people with dementia in Ireland is unclear, as the latter are not differentiated in national data collection.

Although inquiries for this review have shown that some HSE data on home care services (stratified by age and locale) is being collected, the methodology used to collect this data is limited, resulting in ambiguity and a lack of clarity with regard to the information generated. For example, data on service users classified by care group is available but the care categories recorded, such as (i) older people; (ii) disabilities; (iii) mental health; (iv) children; and (v) families; and (vi) others, are not mutually exclusive and, therefore, caution needs to be exercised in interpreting the data. Another problem identified is that no data is available on people with an intellectual disability and dementia and those with early onset dementia (aged less than 65) who are also in receipt of home help services. A further problem encountered by the researchers in attempting to undertake this review is that HSE data is not readily available. Researchers and anyone working to improve the health and social care system need to have better and more immediate access to data collected by the HSE.

In 2011, the HSE published a document summarising information on a range of performance indicators and providing useful data on community care services used by older people. This same document rightly argued that all health care systems “depend upon and run on good information” (HSE, 2011: 3). Our review work for this report leads us to conclude that there is an urgent need for the HSE to generate more dementia-specific data. Specifically, there is a need to collect reliable information on numbers of people with dementia using home care services, the types of home care services (short term or long-term care packages) being received and the numbers on waiting lists for such services. There is also a need to collect reliable data on which service providers (public, private, voluntary) are delivering these home care services.

## 5.5 Day care services

In the context of the 26,000 families we now know are living in the community in Ireland supporting a relative with a dementia, day care has a vital role to play in helping to sustain home and community care. The service affords family caregivers a break from the sheer hard physical labour of caregiving and provides their relatives with much needed psychosocial stimulation. Indeed, effective day care is said to be one that is well planned, accessible, affordable, and is responsive to both the needs of family caregivers and those of their clients – the person with dementia (O’Shea and O’Reilly, 1999).

<sup>34</sup> The main changes included in the Guidelines are: (1) a national standard application which will be used for all new applicants to the scheme; (2) client information booklets; (3) a standard format for reporting outcomes of the client care needs assessment; (4) standard access criteria based on care needs; (5) nationally applicable definition of what constitutes a HCP; and (6) standard approaches regarding frequency of reviews and management of complaints. The implementation of these Guidelines is intended to ensure that applicants for HCP are treated in a similar way regardless of their geographical location and that those with the greatest care needs will benefit from the scheme (Timonen et al., 2011).

Ireland has three main types of day care services, namely: (i) generic; (ii) dementia-focused; and (iii) dementia-specific. Whilst generic day care offers services to the general population of older people, and may or may not accommodate people with dementia, dementia-focused day care either operates on specific days for people with dementia or reserves place for them on a daily basis. The third type of day care – dementia-specific - caters exclusively for people with dementia (O’Shea and O’Reilly, 1999).

### 5.5.1 Data on day care services

In undertaking the review work for this report, it has become evident that there is no reliable data on numbers of people with dementia using day care services in Ireland. Whilst the HSE in its recent nationwide Day Care Survey has shown that about 21,793<sup>35</sup> older people are currently availing of day care services, no detailed information is available<sup>36</sup> on what proportion of this group has a dementia. Data is available on the number of day care centres and places that are specifically designated for people with dementia. Analysis of this data shows that few day care centres (30 out of a total of 464, i.e. less than 10%) are dementia-specific and even fewer (only six) day care centres across the country are dementia-focused. As far as we are aware, all of the dementia-specific day care centres operate under the auspices of the ASI and almost all receive funding from the HSE,<sup>37</sup> whereas all of the dementia-focused day care centres are operated by the HSE. In total, there are approximately 1,727 places in dementia-specific/focused day care centres (although not all of these places are filled), with at least 910 individuals benefiting, i.e., less than 4% of all people with dementia estimated to be living at home.

The data collected via the HSE Day Care Survey also reveals that there is much regional disparity with respect to availability of dementia-specific and dementia-focused day care services. Many of the 32 HSE LHO areas do not have any either dementia-specific or dementia-focused day care centres. As an example, County Roscommon, known to support a large number of people in the older populations with dementia, has neither dementia-specific nor dementia-focused day care. Likewise, LHO areas in other parts of the country such as Dublin South City, Dublin West, Laois/Offaly, Clare, South Tipperary, and West Cork have no dementia-specific day care centres and several of these LHOs have large numbers of older people living with a dementia. There is also much variation in the number of days per week that dementia-specific/focused day care centres operate, although the majority open daily (apart from weekends), some only offer day care services for people with dementia once a week. The range of services offered by dementia-specific and dementia-focused day care services also varies considerably with some offering medical and nursing care, chiropody, physiotherapy, and occupational therapy services and transport, while others have none, or only a limited number, of these services.

Overall, day care provision for people with dementia - generic, dementia-focused or dementia-specific - is low in Ireland, despite a recommendation in *A Vision for Change* that ‘there should be an appropriate provision of day care centres in each mental health catchment area’ (Government of Ireland, 2006). Even where services exist, they may not always be used. Lack of knowledge about the availability of day care services, geographical distance of day care services, transports problems including high transport costs are all factors contributing to the low levels of utilisation of day care services by people with dementia (Kelly and Moran, undated). There is no doubt that day care, like respite care, is underprovided in Ireland, given the potential benefits associated with its use.

The issue of designing day care services responsive to the unique needs of younger people with dementia in Ireland also needs to be considered in service planning and development. Recent Irish research has shown that dementia-specific day care – a service offered by the ASI - accommodates only 3% of the 3,500 people in Ireland known to have early onset dementia. Research has also shown that even when places are available, these day care centres are often unsuitable and inappropriate for younger people with dementia, as they lack the appropriate stimulus for this

<sup>35</sup> We understand that this figure is to be revised upwards to approximately 35,000 day care places (Communication from the Department of Health, 12 November 2011).

<sup>36</sup> Drawn from both the HSE Day Care Survey and from the ASI database.

<sup>37</sup> This service is also funded by direct fund-raising activities.

age category (Haase, 2005; ASI, 2011). In recognition of these issues, Haase (2005) recommends the establishment of specific support groups for younger people with dementia, with groups in at least in Dublin, Galway, Limerick, Cork and Waterford. Young Dementia UK ([www.youngdementiauk.org](http://www.youngdementiauk.org))<sup>38</sup>, is an example of an organisation set up to promote the independence of, and support and care for people with young onset dementia and their families. It offers one-to-one support, services for family members, a social club and a café for younger people with dementia.

## 5.5.2 Lessons from other countries on day care and dementia

The Norwegian dementia plan (2007 to 2015) places considerable emphasis on setting benchmarks for the improvement and expansion of day care services for people with dementia. In Norway around one-third of all municipalities offer day care designed for persons with dementia, although most day care centres are small and in practice less than 10% of people with dementia living at home avail of day care (Westerberg, 2009). As part of its Action plan, 28 Norwegian municipalities have participated in a development project between 2007 and 2010, supported by small government grants, to develop new models of day care services (Engedal, 2010). The goal of the Norwegian Dementia Plan 2015 is that every municipality should offer a day care programme and these should be available to the majority of community-dwelling people with dementia. It is our view that since day care is such a universally acknowledged and important community care service for people with dementia, the Irish government needs to develop a similar goal regarding day care service development for the 26,000 people living in the community with a dementia in this country. There are certainly strong arguments that each LHO area in Ireland should have at least one Dementia-specific Day Care Centre, which is purpose-built, small-scale and domestic, has a multi-sensory garden and employs staff specially trained in dementia care. This of course would have to be subject to agreement in accordance with overall service and resource priorities.

## 5.6 Other respite care services

Respite care services can refer to short-term placement in some form of residential setting or alternatively respite care provided in the home to afford family caregivers a well deserved break. In-home respite is a service highly valued by family caregivers (Argyle et al., 2010) since it means that the individual with dementia is not moved from his or her familiar surroundings and yet the service allows the caregiver a short break from the demands of caregiving. While HCPs can and probably are being used for home-based respite care, we have been unable to generate reliable data on the number and frequency of people with dementia currently receiving respite in their own homes. Where in-home respite services are available they are highly valued by recipients and their families and play an important role in keeping people out of long-stay care.

Residential respite (where a person with dementia is admitted to a residential facility for up to two weeks to enable family caregivers take a break) has been critiqued on the basis that it can lead to further disorientation, can aggravate dementia-related challenging behaviours and can be disruptive to the other nursing home residents. Our review for this report shows that in 2008 less than 1,000 (901) of the circa 25,000 nursing home beds in Ireland were respite care beds. About two thirds (61%) of these respite beds were provided in public sector nursing homes followed by about one quarter (27%) provided by private sector nursing homes. The smallest proportion of respite beds (12%) were found in voluntary nursing homes (Department of Health and Children, 2009: 15). Whilst it is likely that a large proportion of these people admitted for respite have a dementia, the latter is not differentiated in national monitoring systems. We are also aware that the ASI has in recent years been offering residential respite care services to people with dementia. These services are for the most part provided in its Dublin-based centre which has 12 residential respite beds available seven days per week. A new day respite and residential respite centre has recently opened in Tipperary. In addition to directly providing residential respite services in these two centres, the ASI in partnership with

<sup>38</sup> Formerly known as the Clive Project, Oxfordshire.

the HSE provides residential respite care for people with dementia in private nursing homes in four other locations around the country.

So far, we have discussed the health and social care services available to those families in Ireland living at home with a relative diagnosed with dementia and in these discussions we have highlighted high risk groups including people with early onset dementia, those living alone, and those who have no primary caregiver. Another particularly disadvantaged group in Irish society at risk of being overlooked by mainstream and specialist service providers are people with an intellectual disability who develop a dementia. The next section of this chapter reports on literature findings in relation to this particularly vulnerable group of people.

## 5.7 Community care for people with an intellectual disability and Alzheimer's type dementia

In Chapter 2, we estimated that there are approximately 5,500 people with Down syndrome in Ireland, of whom a large proportion will at a comparatively young age develop an Alzheimer's type dementia. In reviewing the literature for this report, it is obvious that the health and social care needs of this particularly vulnerable group of people has received much less attention compared with topics relating to their assessment and diagnostic needs (Strydom et al., 2009). It is noted that people with intellectual disability and dementia often fall between the cracks of different service delivery structures including intellectual disability services, generic community care services for older people and those specifically for people with dementia. Like older people, the social care services required by those with an intellectual disability and dementia include in-home supports, day care services and respite services. However, there is a dearth of published literature available to inform the development of services for this group of people (Jokinen, 2005; Llwellyn, 2011). Hence, there is little evidence for policymakers and services providers to use effectively in developing dementia care services for people with intellectual disability (Jokinen, 2005).

Current thinking suggests that people with intellectual disability who acquire a dementia are best cared for by service providers who have specific intellectual disability expertise (Dodd, 2003; Kerr et al., 2006; McCarron and Lawlor, 2003; Watchman 2003). However, professionals working in this specialist field lack knowledge and skills in dementia care (De Siún and Manning, 2010). This highlights the need for better dementia training and support for staff working in intellectual disability services. In recognition that intellectual disability services may not have the required resources and/or dementia expertise, there is general agreement that people with intellectual disabilities and dementia should have the same access to specialist dementia services as those without learning disabilities (Llwellyn, 2011). However their age profile, interests and special needs may make them ineligible for or unsuited to community based dementia services.

In this context, the importance of cross agency and interdisciplinary liaison is often highlighted (Llwellyn, 2011). There is a need for intellectual disability services to network effectively with primary care health services and generic and dementia-specific community care services. There is also a need for improvements in links between dementia specific organisations such as the ASI and intellectual disability and Down syndrome organisations such as the Down Syndrome Ireland (Janicki and Wilkinson, 2007). Other recommendations include support for national organisations to frame and initiate efforts that focus on intellectual disability and dementia as an issue and make available education and training programmes on ID-dementia for ASI members. Intellectual disability services are encouraged to pro-actively prepare for dementia care (Janicki and Dalton, 2000). Different and useful service models have been identified (Janicki et al. 2002; Kerr et al., 2006), including 'ageing in place', 'in place progression' and 'referral out' models.

## 5.8 Services at the end-stage of life

A growing area of concern centres on the need to provide services to people with end stage dementia living in the community. Although palliative care services were originally developed for people with cancer, it is now widely accepted that palliative care has an important role to play in the care of people with a dementia (Hughes, 2006; HSE and IHF, 2008). In this context, the *Palliative Care for All* and *Palliative Care and Dementia* documents are very useful frameworks within which to develop services aimed at caring for people with dementia at the end stage of life in all care settings, including in the community. Another project on palliative care due for completion in March 2012 aims to build consensus among key stakeholders on policy relating to palliative care for people with dementia in Ireland. This ASI feasibility project, *Dementia Palliative Care in Ireland – Building Consensus for the Future*, is being funded by the IHF.

Most people in Ireland, including those with dementia, would prefer to live and die in their own home. Whilst it may be possible for some people to remain in their own homes even with a very advanced dementia, the majority do not live out their last days at home. Whilst data on the place of death of people with dementia is not available in Ireland, an English study, which followed up a sample (N=91) of people with dementia who at recruitment were living at home found that three quarters had entered an institution (hospital or nursing home) permanently before death (Keene et al., 2001). Some experts have argued that the fact that people with dementia do not die at home needs a great deal more consideration (Hughes et al., 2007: 257).

There has been little research undertaken internationally focusing on the obstacles and facilitators to home based end-of-life care for people with dementia or research investigating the experiences of community dwelling people with dementia or their carers leading up to the last days of life (Goodman et al., 2010). We know, however, that there is a widespread scarcity of palliative care interventions in Ireland for people with dementia living at home and this may be a factor in decisions made by families to arrange nursing home care for people with dementia (MacConville, 2011). We also know that the ASI in some instances continues to provide home care services to people with dementia up to the time of death, and while palliative care services within its current service system is underdeveloped, the ASI is committed in the future to the development of such services.

## 5.9 Other community care services

Occupational therapists, social workers, physiotherapists and speech and language therapists have each an important role to play in the care and support of people with dementia in the community. Occupational therapists are concerned with the care of the whole person; their emphasis tends to be on activities of daily living, including dressing, eating, grooming and on home adaptations and helping the individual with a cognitive impairment to compensate for the cognitive deficit and engage in meaningful activities. Their main aim is to restore and reduce the decline in the person's functional ability. They may also have a role to play in assessing suitability for assistive technology. Begley's recent research showed that in the Dublin metropolitan area, there were long delays experienced in accessing this service which meant that some people had to resort to purchasing in the occupational therapy service privately (Begley, 2009). Social workers have an important role to play in needs assessment, in advising people about their service entitlement; in protecting the rights of people with dementia and safeguarding the health and welfare of primary caregivers. Whilst recent years have seen an expansion in the number of Social Worker appointments in HSE areas, these appointments are exclusively in the area of elder abuse and are not dementia-specific. Physiotherapists' main aim is to maximise the person's abilities to allow the greatest level of independence possible and Speech and Language therapists focus on improving quality of life by maximising communication ability and cognitive function. It needs to be emphasised that public access to the aforementioned allied health service providers in the community remains extremely limited (O'Shea and O'Reilly, 1999).

Some countries (e.g. Sweden, the Netherlands, Norway and Wales) explicitly emphasise the important role that specifically-trained occupational therapists, social workers and physiotherapists play as part of community care teams and community mental health teams with regards to assessment, diagnosis and ongoing care of people with dementia. In Ireland, *A Vision for Change* recommended the inclusion of occupational therapists and social workers and input of physiotherapists in community mental health services teams (Government of Ireland, 2006). In Scotland, funding has been provided for three Allied Health Professions (AHP) Consultants Post in Mental Health (Dementia Care) to provide leadership and maximise the impact of the allied health professionals in dementia care. The role of the AHP consultants, working in partnership with all key stakeholders, is to review the contribution of the AHPs in the care of people with dementia, work towards enhancing current models of practice as well as consider new models that could be developed.

Finally, a group of disparate community initiatives dedicated to supporting families living with dementia are beginning to mushroom in specific geographic locales in Ireland. Some of these initiatives are statutory, others voluntary using ring-fenced and limited budgets and yet others are funded for a specific time period by philanthropic organisations or under EU programmes. Some have a psychosocial supportive function whilst others are designed to provide more practical solutions to people living with a dementia and for their family caregivers. The following section reports on some of these initiatives.

**(i) Social Clubs** have been established in recent years by the ASI. These are clubs attended by couples where one or other partner has a dementia and have been designed to cater for people in the earlier stages of dementia and to address the social isolation experienced by both the person with dementia and their carer. The social club model has been formally evaluated (Keogh and McGettrick, 2008) and findings demonstrate benefits gained from providing a dementia friendly social network including an opportunity to socialise ‘worry-free’ and for caregivers to learn and share their respective skills and experiences.

**(ii) The Alzheimer Café**, an international concept, has recently been launched in Ireland (see [www.alzheimercafe.ie/](http://www.alzheimercafe.ie/)). The Alzheimer Cafe is a platform for support, advocacy, education, information, empowerment, and for openness and inclusion rather than avoidance. It is a collaborative initiative currently led by a group of health service professionals aware of the critical need for more social supports for both people with dementia and their family caregivers in Ireland. The initiative is supported by: the DSIDC, the ASI, Sonas aPc, the Third Age National Advocacy Programme,<sup>39</sup> the HSE and NHI.

The Café has been trialled in Donnybrook in Dublin and offers a safe and relaxed place where people with dementia and their families can meet in the presence of health and social care professionals for a once-monthly meeting in a café-style environment. It offers support, information and works towards achieving more openness about dementia. It offers a unique blend of education, therapeutic support and information for people who know that they themselves or a family member has a diagnosis of Alzheimer’s or another dementia. The Alzheimer Café is independent from and designed to complement other existing services and supports, including day care centres, respite, home care and social clubs.

**(iii) Remembering Together:** This is an EU funded project being led in Ireland by staff at the DSIDC’s Living with Dementia Programme based in TCD. It entails bringing together a group of couples where one or other partner has a dementia and where family members are taught the benefits of using Reminiscence Therapy in their day-to-day interactions with their spouses. Ireland is one of 10 European countries involved in this project. The project will ultimately lead to the development of a training manual for caregivers on Reminiscence in Dementia. The project has been very positively evaluated.

<sup>39</sup> Formally known as the National Advocacy Programme Alliance



**(iv) Psycho-educational programmes:** A recent initiative of the ASI is the Training of Family Caregivers – a programme available free of charge which to date has trained up to 450 family caregivers. An additional attraction is that respite care is offered by the ASI to family caregivers to ensure that they are free from caring and available to attend the course. To our knowledge there are few other similar training programmes available to family caregivers of people with dementia in Ireland apart from this one. The active participation (using role play and experiential learning) of family caregivers in training sessions as compared with educational interventions which focus exclusively on information provision have been found to have very positive effects on caregiver burden, depression, subjective well-being, coping abilities and knowledge about dementia, and symptoms of the care recipient (Pinquart and Sörenson, 2006).

We are also aware that where other excellent training programmes have come on stream not all family caregivers can avail of such training as they are unable or unwilling to access appropriate substitute respite services to free them from the heavy demands of their all encompassing care role.

**(v) The Netwell Centre** (<http://www.netwellcentre.org/>), based at the Dundalk Institute of Technology (DkIT) in County Louth, is involved in a number of projects that aim to reduce the social isolation of older people, including those with a dementia. Initiatives include practical help to older people, such as the Cúltaca service which seek to fill service gaps where a need is identified.

**(vi) The Genio Dementia Project:** This is a new and exciting project based on a community development model. It is jointly funded by the HSE and by AP. The project aims to test and develop new services models designed to maintain people with dementia at home for longer by improving the range and quality of community based supports for people with dementia. The project also aims to influence policy and investment in this area to build capacity and leadership in the field of dementia care in Ireland.

**(vii) Cognitive Stimulation Programme:** Some HSE-based occupational therapists and clinical psychologists provide individualised cognitive stimulation programmes. Several Memory Clinic services offer counselling services and advice to people to help them compensate for their memory deficit. The Memory Clinic based at Dublin City University is about to commence a Psychotherapeutic programme designed for people with dementia and their family caregivers.

**(viii) The Telecare Project:** This project is currently being carried out by the ASI in conjunction with Emergency Response and is funded under the EU co-ordinated e-care programme, “Independent”. The project makes telecare aids and appliances available free to people living in the community, known to the ASI who are diagnosed with dementia. Following assessment and consent from both the person with dementia and the family caregiver, telecare equipment is installed in the person’s home and used to monitor activities, e.g. how often a gas detector is activated. The aim of the project is to assist people with dementia to live independently and safely and to offer reassurance. The project is to be evaluated.

## 5.10 Summary and conclusion

In conclusion, we believe that, like in other countries, most of the complex needs of people with dementia and their family caregivers can be met by primary and community care services. However, services need to be individualised, comprehensive, accessible, flexible and delivered by competent well-trained staff. In the context of community care, GPs are critical agents in the development of pathways to care as they are generally the first point of contact for the individual or for family members worried about the signs and symptoms of dementia and are in strategic positions to refer families to suitable community-based practitioners. So too are nurses, but the absence of dementia-specific training and appointments in community-based nursing is far from optimal given their strategic importance to comprehensive and integrated care. There is a need for realistic and adequate resources to be invested into providing

good community care services to people living at home with dementia. People with dementia receive very few in-home formal support services and certain schemes which have the potential to reduce caregiver burden and prolong community care such as HCP lack the flexibility and specificity to address the fluctuating needs of many people with a moderate and severe dementia. Day care and respite care remain underdeveloped, their potential unrealised in the holistic care of people living at home with dementia.

The consequences of an underdeveloped and fragmented community care system are that significant and, in the long-term, unsustainable care burdens fall disproportionately on family carers. Little wonder, therefore, that for some carers the burden becomes unbearable, resulting in some people with dementia being admitted to long-stay care that could and should be cared for at home if adequate support services were available. In the short-term, given scarcity of resources, choices will have to be made about the reallocation of some of the existing institutional resources to community care. This will be painful and so will have to happen gradually, but spending on one person with dementia in the community can reach €50,000 per annum before institutional funding thresholds are reached. That is not an inconsequential allocation to help develop community-based services. Furthermore, given what could be achieved through relatively low-cost case management and integrated delivery, the development of a world class community-based care does not seem so farfetched after all. This is what we should be aiming for in the medium-term.



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# CHAPTER 6

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## SERVICES FOR PEOPLE WITH DEMENTIA IN ACUTE CARE SETTINGS

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They weren't able to cope with the dementia side of things and they'd have been ringing me up at all hours of the night to say X wants to speak to me you know and sometimes she would be pacified but when I would go in she was usually in a terrible state wandering about. That was a very difficult time.

*Family carer of person with dementia*

”

## 6.1 Introduction

Given the relationship between (i) dementia and age; and between (ii) age and admission to acute care settings, it is likely that many hospital patients in Ireland will have dementia, or an associated cognitive impairment. It is difficult to estimate how many people with dementia occupy acute hospital beds at any given point in time, but estimates suggest that up to 25% of all patients in a typical general hospital may have dementia. The number of men and women with dementia admitted to hospital with a primary diagnosis of dementia is, as we have seen in earlier chapters, much lower leading to the invisibility of this group of patients in official statistics. This is because the reasons that people with dementia are admitted to hospital are more often than not related to some co-morbidity rather than to the dementia. In an Irish study conducted several years ago, Hickey et al. (1997) found that for the majority of people with dementia, a medical condition precipitated hospital admission. Like people who are cognitively intact, there are a range of medical and/or social reasons that prompt the admission of people with dementia to hospital. These include heart disease, cancer, hip fractures due to falls, and psychotic symptoms related to alcohol use (Thompson et al., 2010). Sometimes, it is only following admission that a dementia is discovered; for example, 15.8% of patients admitted to an orthopaedic hospital in Ireland for elective or traumatic surgery had evidence of significant cognitive impairment (Hickey et al., 1997).

It has also been noted that the prevalence of dementia amongst patients in an acute hospital is likely to increase with age, as shown by Sampson et al. (2009) who found that 42% of individuals aged 70 years and over with an unplanned admission to an acute general hospital in England had dementia. This figure rose to 48% for those over 80 years (Sampson et al., 2009). The prevalence of patients with dementia across acute hospital wards varies widely and is dependent on the type of ward and the demographic profile of patients on the ward (Mukadam and Sampson, 2010).

In recognition of the prevalence of dementia in general hospitals and in an effort to improve hospital dementia services, countries including England, Scotland, Northern Ireland, Norway and Australia have identified improvements in care for people with dementia in general hospitals as key policy objectives in their National Dementia Strategies. Different aspects of dementia care in acute hospital settings are emphasised in these different countries. For example, Scotland's National Dementia Strategy is of particular interest as it has identified 'care in general hospital settings' including: (i) alternatives to admission; and (ii) better planning for discharge, as key service delivery areas in which immediate change is required.<sup>40</sup>

## 6.2 Detection of and assessment for dementia

Significant cognitive impairment often goes undetected before admission to a general hospital (Hickey et al., 1997; Sampson et al., 2009). In a retrospective study in Ireland, Afzal et al. (2010) found that only 54% of people over the age of 65 who had died on an acute medical ward had a MMSE carried out during their hospital admission. Bentley and Meyer (2004) found that assessment for dementia is not often considered for many older people attending A&E, even when there was frequent re-attendance by patients and worrying signs of possible dementia such as falls, dehydration, self-neglect or a pattern of non-compliance with treatment were present.

Even where cases of dementia are known, they are not always recorded or communicated to hospital staff on admission (Thompson et al., 2010); indeed, it is said that sometimes dementia is known to staff in one part of the hospital but is not communicated to staff in other departments (Bentley and Meyer, 2004). There are many reasons why hospital staff should be made aware if patients have a dementia, not least the fact that patients with dementia admitted to hospitals are at an increased risk of developing delirium and it is important that signs of delirium are detected early and appropriate care is provided (Cunningham and Archibald, 2006; Moyle et al., 2008; Thompson et

<sup>40</sup>The Scottish Government (2010).

al., 2010). The National Audit of Dementia Care in General Hospitals in Wales and England found that the majority of hospitals had a stated policy of mental state assessment for patients with a dementia, but the reality as reflected in case notes showed that fewer than half had received a standard cognitive test, and very few had been assessed for delirium (Royal College of Psychiatrists' Centre for Quality, 2010). Worryingly, the National Audit Office (2007) found that some general hospitals in the UK worked hard not to make a diagnosis of dementia, for fear it would delay discharge.

The importance of improving the assessment and diagnosis of patients admitted to hospital who might have dementia (particularly when emergency admissions occur through A&E) is recognised in the Scottish National Dementia Strategy, as a gateway to better care and support. In Scotland a key piece of work has been on training general hospital staff to recognise the symptoms of dementia and to provide dementia-friendly care in hospital settings (Scottish Government, 2011b). Through the improvement of patient information systems (Scottish Government, 2010), the Scottish National Dementia Strategy also aims to ensure that all staff have good quality information about a person's diagnosis.

### 6.3 The role of primary and community care

There is no doubt that hospitalisation of people with dementia is often unavoidable and necessary and in those circumstances people with dementia have as much right to acute hospital care as everybody else. Notwithstanding this, the quality of primary care is an important factor determining admission to hospital for people with dementia (Thompson et al., 2010), as is the level of stress that family caregivers are subjected to due to the heavy demands of dementia care (Bobersky and Cahill, 2011). Based on their research on prevalence of dementia in acute general hospitals in Ireland, Hickey et al. (1997: 31-2) drew the following important and enduring conclusion:

... there must be a strong possibility that many of these admissions represented the "last straw" rather than fresh medical conditions which would have caused the admission of an equivalent patient without dementia. In such circumstances, where there are no rapidly available support systems, carers would be under great strain even when relatively minor acute illnesses affected their ... relative [with dementia]. In this setting there would be a tendency for family doctors to opt for hospital admission as the only form of relief of the situation.

Levels of unmet needs among older people with dementia living in the community are significant, as shown in Chapter 5. These include self-care and toileting needs, behaviour and mental health needs, thinking and memory needs, and social interaction needs (Meaney, Croke and Kirby, 2005). An interesting observation is the importance of balance/falls as a predictor of hospital usage. Poor balance in community-dwelling people with dementia is important as it is associated with an increased rate of falls and hip fractures and with hospitalisation and institutionalisation (Meaney Croke and Kirby, 2005).

The provision of integrated community-based systems of support for people with dementia would almost certainly reduce demand on acute hospitals. The importance of a multi-disciplinary approach to the management of the person with dementia living in the community and the appointment of a Case Manager would help to identify multiple needs and coordinate the provision of appropriate responses. The view that hospital admission of people with dementia might be delayed or prevented if primary care services were improved, particularly by means of increased knowledge about dementia care and improved communication strategies among providers, is supported by others (see, for example, Thompson et al., 2010). An evaluation of the Dementia Rehabilitation at Home (DRAH) project in Australia, piloted under the Innovative Pool Dementia Pilot,<sup>41</sup> revealed that outreach and community-based specialist dementia

<sup>41</sup> In Australia, a Dementia Pilot established under the Aged Care Innovative Pool formed part of the national response to meeting the needs of people with dementia. The Innovative Pool was established in the financial year 2001–02 to target older people with rehabilitation needs and other high and special needs groups through a national pool of flexible care places outside of annual Aged Care Approvals Rounds. In 2005 dementia was named a National Health Priority.

services reduce the use of hospitals by people with dementia, leading to improved patient outcomes (Hales, Ross and Ryan., 2006).

In some countries, there is an emphasis on reducing unnecessary hospital admissions (Scotland, Sweden and Australia). In Scotland, for example, work aimed at improving general hospital's response to dementia includes supporting alternatives to hospital admission. The Enhanced Assessment and Support Team (a jointly-funded health and social work team) in North East Fife is an example of such an initiative in Scotland. The team provides community assessment and short-term care to older people with dementia and other mental health difficulties. Improved outcomes for people with dementia and carers using the service include reduced in-patient beds, reduced length of hospital stay and reduced day hospital attendances (Scottish Government, 2010).

### **Box 6.1 Example of good practice from Australia: Dementia Rehabilitation at Home (DRAH) Project, New South Wales**

This rural area of New South Wales was marked by low level service provision with poor access to medical specialists and mental health services. There were waiting lists of up to four months to access geriatric and psycho-geriatric services, and many people with suspected dementia had not received a formal diagnosis. DRAH was set up: (i) to help people obtain a medical diagnosis of dementia, dementia-related symptoms and related co-morbidities; and (ii) to link people with dementia and their carers into a formal support network.

There are two main components to DRAH: intensive clinical assessment and community-based, in-home services. Access to the DRAH multi-disciplinary team, consisting of a gero-psychologist, social worker, occupational therapist, and a physiotherapist with assistance from geriatric and dementia-specific services accessed through Telehealth, is also an integral part of the project. People with dementia and caregivers are assisted by the DRAH multi-disciplinary team to develop rehabilitation goals, commencing with their receiving an accurate diagnosis and progressing to treatment for behavioural symptoms, and the organisation of in-home services. Beneficial outcomes include differential diagnosis, advice on planning ahead, advance directives and driving issues; medication review and advice. Referrals to DRAH come mostly from GPs and hospital A&E departments. It is estimated that during its first year, DRAH saved an estimated 204 acute care days (Hales, Ross, and Ryan, 2006)

## **6.4 Care and outcomes for people with dementia in acute care settings**

Adequate and appropriate community support is particularly important in the context of good dementia care, as research evidence demonstrates that people with dementia once admitted to acute hospitals often have far worse outcomes than those without dementia. Although no figures are available comparing the length of stay of people with and without dementia for similar procedures in Ireland, there is evidence from the ESRI's Annual Report on Activity in Acute Public Hospitals in Ireland 2009 showing that the length of stay in hospital for people diagnosed with 'dementia and other chronic disturbances of cerebral function'<sup>42</sup> is much greater than that for all people aged 65 years and older. In general, people diagnosed with dementia and other neurological problems spent significantly longer (on average 41.1 day) (ESRI, 2010: 168) in hospital compared to people aged 65 years and over, for whom the length of

<sup>42</sup> Dementia and other chronic disturbance of cerebral function is a Diagnosis Related Group, that is, a 'cluster of cases with similar clinical attributes and resource requirements. The Australian Refined Diagnostic Related Group (AR-DRG) is used in the ESRI report.

stay in hospital was on average 10.9 days (ESRI, 2010: 53). More evidence is needed on the extent to which length of stay in hospital is longer for people with dementia as compared with those who are cognitively intact for the same procedures including surgery (Alzheimer's Society, 2009). Similarly, more information is required on whether people with dementia have higher mortality after acute medical admission (Sampson et al., 2009).

People with dementia are particularly sensitive to their built and psychosocial environment (Judd, Marshall and Phippen, 1998) and need a stable, consistent, familiar environment easy for them to negotiate and one that ideally reinforces their identity. Accordingly, it is not surprising why an admission to hospital can cause them enormous distress and can aggravate their disorientation and precipitate or aggravate challenging behaviours. The hospital environment complete with multiple and competing stimuli including noises (such as call bells, moaning, swinging doors, discordant television and radio, trolleys clattering), ward rounds, visitors coming and going, staff changeovers, cluttered ward layouts and poor signage are far from ideal for a persons with a cognitive impairment and can be experienced as frightening and hostile. Even cognitively impaired people who were functioning well in their home environment prior to hospitalisation often become extremely confused and unsettled in a general hospital setting (Thompson et al., 2010). Not surprisingly, therefore, people with dementia who were living independently in their own homes prior to admission to hospital are less likely to return home following hospital discharge (MacNeill and Lichtenberg, 1997).

Research in Scotland found that over a third of people with dementia who were admitted to hospital from home were discharged to a residential care setting (Alzheimer Scotland, 2009). This may be partly attributed to the de-skilling that results from a prolonged stay in hospital (Thompson et al., 2010) and the absence of cognitive-based programmes within acute care settings. A feature of the acute hospital provision is the low level of attention given to cognitive impairment among older people in that setting, mainly due to time constraints among staff and the absence of appropriate knowledge and training. The general consensus of people with dementia and their carers participating in this year's National Dementia Summit is that much work needs to be done to create a better understanding of dementia and cognitive impairment among health service professionals, including those working in acute hospitals (ASI, 2011).

Reducing hospital length of stay, and careful timely discharge planning is a feature of the National Dementia Strategies in England, Scotland and Northern Ireland. For example, the Scottish National Dementia Strategy states that 'when someone with dementia admitted from home is discharged from hospital, facilitating that person's return home should be the starting point' for hospital staff, and discharge planning needs to be designed to ensure that decisions about a longer term approach to care are not taken immediately. Better forward planning with and for people with dementia during hospital admission was thus identified as an area where there is significant scope for improvement in Scottish hospitals (Scottish Government, 2010: 41).

The Scottish Standards of Care for Dementia apply to people with dementia in all care settings, and include standards specific to the general hospital setting (Scottish Government, 2011a). The Chief Nursing Officer is to oversee the implementation of the dementia standards in general hospital settings and will lead a programme of work to give assurance that care for older people in these settings, irrespective of their having a formal diagnosis of dementia or not, meets the highest standards of care and compassion (Scottish Government, 2011c).

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**Box 6.2** Examples of good practice for dementia care in acute hospitals

The Hospital Elder Life Program (HELP) in the US is a model of care aimed at preventing cognitive as well as functional decline in older people hospitalised and is designed to maximise independence at discharge. It aims to assist with transition from hospital to home and prevent unplanned readmissions. It has been found to be successful in reducing staff burden and promoting a positive cultural change through ongoing education and multidisciplinary collaboration (Moyle et al., 2008).

Progressively Lowered Stress Threshold (PLST), first developed in the 1980s in the US. According to the PLST model, people with dementia are less able to manage stress as the condition progresses. The PLST model of care advocates a modification of the hospital environment to take account of the progressive decline in the person's cognitive impairment and to lessen the number of stressors to which older people in hospital are exposed (Smith et al., 2004; Moyle et al., 2008).

We have no Irish research reporting on the perspectives of Irish men and women with mild to moderate dementia admitted to hospitals, a situation which it is hoped will be redressed in the not so distant future following the pioneering work of a group of clinicians and researchers from Cork.<sup>43</sup> However, older spouses of those with dementia participating in one recent Irish study reported very unpleasant experiences of hospitalisation on the well-being of the person with dementia, and referred in particular to the inappropriate hospital environment, and lack of necessary knowledge and skills of hospital staff to care for people with dementia (Cahill, Doran and Watson, 2010). Direct evidence from people with dementia in the UK paints a bleak picture of the experiences of people with dementia in the acute hospital setting. The research showed that being in hospital was an unhappy time for people with dementia characterised by feelings of neglect, being confined to a disturbing environment and a great feeling of uncertainty (Cowdell, 2010).

The interactions between nursing staff and hospital patient and between care assistants, domestic and catering staff and hospital patient (many of whom have the most frequent number of contacts with hospital patients) all have a major impact on the individual with dementia's experience of being on a hospital ward. While there is some evidence of more person-centred care, attitudes of staff towards people with dementia in general hospitals are often seen as more negative than positive in Ireland (Nolan, 2006) and elsewhere (Cowdell, 2010; Fossey, 2008; Moyle et al., 2010). People with dementia in acute hospitals report interactions with staff to be minimal and focused on physical care despite efforts of patients to express other needs. Negative communications such as ignoring, disempowerment, infantilisation and stigmatization gradually undermine the individual. One of the implications of negative interactions is that people with dementia are likely to withdraw into themselves and reduce their efforts to communicate (Cowdell, 2010).

In an Irish study exploring nurses' experiences of care for older people with dementia in a large acute hospital setting (Nolan, 2007), the nurse participants reported many limitations imposed on them by the hospital setting which made it difficult for them to carry out nursing care of people with dementia. They were aware that the typical activities of a busy acute care setting can be over-stimulating for a person with dementia and lead to increased disorientation. Visiting times and doctors' rounds offer examples of how the acute hospital environment can present the person with dementia with particular difficulties. The physical layout of hospital units (including geriatric units) was unsuitable for

<sup>43</sup> This much needed research programme, first piloted in 2010, is designed to estimate the prevalence of dementia and delirium in hospital settings in Cork and to identify the determinants of challenging behaviours in hospital settings. As part of the programme the views of patients with dementia and their family caregivers will be elicited.



people with dementia. A concern with patient safety restricted the free movement of people with dementia within the acute hospital setting. Participants reported that the level and activity of nursing work precluded nurses from prioritising people with dementia or giving them the time needed to provide quality care (Nolan, 2007). Similarly, environmental, socio-cultural and resource constraints to best practice have been identified by health professionals providing care to people with dementia in acute hospitals settings in other countries (Borbasi et al., 2006). Nolan (2006: 213), however, found that, despite the contextual challenges inherent in caring for older people with dementia in acute care settings, 'nurses ... persisted in their attempts to promote personhood and build relationships with persons with confusion'.

For similar reasons, the A&E setting, complete with call alarms, complicated clinical equipment, patients moaning, echoing and yelling, attempts at resuscitation and distressed relatives, is a particularly frightening and challenging environment for people with dementia. Yet, simple achievable actions can be undertaken by staff to improve the support to people with dementia in A&E settings (Cunningham and McWilliams, 2006) as well as on acute hospital wards. The Scottish Cross Party Group on Alzheimer's has made a number of recommendations on the most appropriate care of people with dementia attending A&E and the Scottish Government has endorsed and provided guidance to support delivery of these recommendations in NHS Scotland general hospitals.

### 6.4.1 Risk of dementia for hospital patients undergoing anaesthetics

Our ageing population also means that increasing numbers of older people, including those with dementia, will require surgical procedures in hospitals and in so doing will be exposed to general anaesthetics. Whilst the Anaesthetists would argue that the jury is out regarding the adverse effects of anaesthesia on older people (Avidan and Evers, 2011), there appears to be some chilling and convincing evidence that age is a risk factor for late post-operative cognitive dysfunction (Moller et al., 1998). Accordingly, whilst surgery and anaesthesia have done much to improve the length and quality of life of many people of all ages there is growing concern among scientists, anaesthesiologists, neurologists, neuropsychologists and surgeons about the number of reported cases of post-operative cognitive decline (POCD), especially long-term POCD occurring in older people undergoing anaesthetics.

In this context, careful consideration is now being given to anaesthetics as yet another possible risk factor for Alzheimer's disease, particularly amongst older people. Recent evidence has emerged that inhaled anaesthetics are suspected to potentially accelerate Alzheimer's disease (Mandal and Fodale, 2010; Fodale et al., 2010). In the absence of conclusive knowledge about the relationship between anaesthetics and Alzheimer's disease, Mandal and Fodale (2010: S136) call for a serious rethinking of the topic and recommend that 'abundant caution in the choice and the procedure is perhaps the key to avoid adding yet another factor to the armamentarium of risk factors for AD'. In addition, consideration needs to be given to the impact of general anaesthetics on patients already known to have a dementia as well as the issue of obtaining consent from them about the use of anaesthetics, and decisions about the use and choice of anaesthetics for them (Funder et al., 2010).

## 6.5 People with dementia and challenging behaviour

We have already referred to the type of challenging behaviours people with dementia admitted to hospital can experience, such as repeated questioning, agitation, wandering, paranoia, hallucinations, delusions, sleep disturbance and resistance to care. One Irish study found that challenging behaviour in acute hospital settings occurred most often in patients admitted with a progressive dementia, whereas patients with 'incidental, stable dementia' rarely had challenging behaviour (McGlade et al., 2009). Insufficient staff numbers and lack of dementia-specific skills in dealing with challenging behaviour were identified by healthcare workers as important issues hindering optimal care (McGlade et al., 2009). Caring for those with challenging behaviours presented particular dilemmas for nurses and other health professionals working in an acute hospital environment (Borbasi et al., 2006; Nolan, 2007). Persons with

dementia who have challenging behaviours in hospital need time to be listened to and time to be better understood. Ideally, they need specially adapted services in small and safe settings. Having a hospital-based dementia champion available to assess such patients and advise and instruct front-line staff on psychosocial interventions and best practice would be hugely beneficial. It is our view that “specialling” these patients is costly and should be the last resort used only when all other psycho-social interventions have been trialled. The National Audit of Dementia Care in General Hospitals in Wales and England found that the majority of hospitals had no protocol in place governing interventions for patients displaying challenging behaviours suitable for use with people with dementia. In those hospitals with protocols, it was specified that restraint and sedation were only to be used as final options and in the best interests of the person with dementia (Royal College of Psychiatrists’ Centre for Quality, 2010).

There are a number of different reasons - some neurological and others environmental - why people with dementia may exhibit challenging behaviours. Some behaviours, for example, are caused by a chemical imbalance in the brain and may be directly related to the dementia but others may be precipitated by a myriad of psychosocial and environmental factors such as room temperature (too hot or too cold), the person’s fatigue or malaise, he or she being in pain, bored or frightened being surrounded by unfamiliar faces. Agitation, aggression, wandering and repeated questioning, for example, may be an expression of unmet need. The big paradox in dementia care is that people with dementia need much time and yet affording this time for person centred care in busy acute care settings poses a serious challenge for many health professionals (Cunningham and Archibald, 2006). Therefore, strategies that aim to facilitate communication are crucial (Moyle et al., 2008). Nolan (2007: 422) concluded that, because of the challenging nature of dementia care and the limitations of the acute care environment, nurses have ‘particular learning needs which need to be addressed to equip them to provide skilled dementia care’.

## 6.6 Staff training, education and ownership of dementia

People with dementia will come into contact with a wide range of staff in A&E and acute hospital wards (McKay et al., 1996), including clerical staff, porters, technicians, nursing or health care assistants and hospital consultants. It is, therefore, important that health service professionals and all staff in general hospitals have the knowledge and skills that enable them to better understand patients with a dementia and enable them to provide good quality care to these people in such settings. Limited staff knowledge and understanding of dementia has been reported as a major constraint to best practice (Borbasi et al., 2006) and highlighted in national dementia strategies in other countries (Department of Health, 2009; Scottish Government, 2010). However, education and training in awareness of dementia and appropriate skills development for dealing with dementia is absent in most acute hospitals in Ireland. We know that staff in general hospitals in Ireland often have a poor understanding of the needs of patients with dementia; the vast majority (95%) of nurses in general hospitals have not received training in dementia care (De Siún and Manning, 2010). The importance of staff education is emphasised in models of care that have been proposed for use with older people with dementia in acute hospital settings. For example, Moyle et al. (2008) identify a number of areas where nurses’ knowledge of dementia could be improved. These include:

- A greater understanding of the clinical syndrome of dementia and how it differs from delirium;
- The effective assessment of mental status;
- Factors contributing to cognitive decline during acute illness and hospital admission;
- Strategies to prevent cognitive decline;
- How to manage older people experiencing delirium or dementia.

Improving dementia care knowledge of staff working in general hospitals is a focus of the National Dementia Strategies in England, Scotland and Northern Ireland. It is believed that addressing staff knowledge and skills gaps in dementia care improves care and outcomes. In Northern Ireland, the Dementia Services Development Centre (DSDC) NI has developed a resource pack for Health and Social Care Trusts to enhance knowledge on dementia and skills

of staff working in the acute sector (DHSSPS, 2011). The Department of Health in England has published a guide to improving quality of care in general hospitals.

In June 2009 the DSDC Scotland launched a resource pack to support staff care for people with dementia in acute care settings. The pack addresses a range of materials including staff knowledge of dementia, the A&E department, promoting dementia-friendly hospital environments and understanding and managing challenging behaviours. The pack contains a guide and a range of multimedia materials that will assist health service professionals supporting people with dementia in NHS Scotland hospitals. Following the launch of the Scottish National Dementia Strategy, the NHS Education for Scotland and the Scottish Social Services Council developed *Promoting Excellence: A framework for health and social services staff working with people with dementia, their families and carers* to support delivery of the aspirations and change actions outlined in the Strategy. The document details the knowledge and skills all health and social services staff should aspire to achieve in relation to the role they play in supporting people with a diagnosis of dementia, and their families, and carers, including all staff in general hospitals and A&E departments (Scottish Government, 2011b).

The lack of ownership and leadership of dementia in general hospitals has been highlighted in research studies (Moyle et al., 2008) and improving quality of care for people with dementia in general hospitals through staff ownership of dementia is an approach adopted in countries such as England, Wales and Scotland. The English Dementia Strategy recommends that senior medical clinicians within general hospitals take the lead for quality improvement in dementia in the hospital, whereas in Scotland the emphasis has been on specialist dementia nurses. In fact, the Scottish Government has provided once-off funding of £300,000 to support Alzheimer Scotland to build on their pilot of specialist dementia nurses in NHS Boards. The role of the specialist dementia nurse is to support significant changes and improvements in the standards of care for people with dementia and their families while in acute general hospital, through specialist advice on care delivery, information, training and support. Evaluation of the existing posts has provided clear evidence of the benefits of specialist dementia nurses. The funding, matched by equal funding from Alzheimer Scotland, is facilitating seven new posts over a two-year period across NHS Boards (Scottish Government, 2011c). Both the English and Welsh National Dementia Strategies recommend the establishment of older people's mental health teams dedicated to specialist liaison in general hospitals.

**Box 6.3 Example of good practice:  
Dementia Champions Programme, NHS Ayrshire and Arran**

The Dementia Champions Programme is a model for promoting hospital ownership of good practice in caring for people with dementia in general hospitals. It was developed to raise awareness of dementia and the needs of people with the condition in the acute hospital setting. Enthusiastic and motivated individuals with a genuine interest in dementia care were nominated by ward managers to become dementia champions in two rehabilitation community hospitals. A staff nurse and healthcare assistant from five wards as well as two generic workers from another hospital within NHS Ayrshire and Arran were also recruited as dementia champions. The main elements of the role are as follows:

- > To be a guide, supporter, mentor and change agent;
- > To challenge poor practice appropriately;
- > To promote the wellbeing of people with dementia;
- > To promote a person centred approach and be a model for good practice;
- > To support relatives and carers to enhance their wellbeing and enable them to continue in their caring role;
- > To raise awareness, share information and knowledge;
- > To provide ongoing support in the workplace.

Caring for People with Dementia in Acute Care Settings (DSDC Scotland, 2010), a DSDC Scotland resource pack, was used to support the dementia champions in their learning. The resource pack promotes a person centred approach and contains practical information on topics such as pain management, nutrition, communication strategies and psychological and behavioural symptoms of dementia. In the uncertain economic climate, the resource pack was considered the most cost effective method of supporting dementia champions (Crabtree, 2010).

## 6.7 Supporting family carers within acute care settings

A common theme in the literature on the care of people with dementia in the acute care setting is continued involvement of family or other informal carers (Moyle et al., 2008). Afzal et al. (2010) found that patients with end-stage dementia were significantly less likely to have their informal carers or family members involved in treatment decisions, suggesting that the lack of involvement by health care professionals of family in the care of people with dementia that occurs at primary care level in Ireland may persist into general hospital care. However, the importance of working with relatives/carers to establish a bond leading to meaningful care has been emphasised by nurses caring for people with dementia in an acute hospital setting in Ireland, as has the role of nurses in supporting relatives/carers (Nolan, 2006). On the one hand, the insights of relatives/carers, described by nurses as integral members of care relationships, enriched caring through the provision of insider information for nurses and enabled them to more easily relate to the person with dementia in an authentic and genuine way. On the other hand, the role loss experienced by family carers when a loved one is admitted to an acute setting requires, at the very least, an acknowledgement by nursing staff. While this is consistent with person-centred care approaches to dementia, the limited opportunities and challenges to engaging directly with family carers in the acute care context must also be acknowledged (Nolan et al., 2004).

**Box 6.4** Example of good practice involving family members of patients with dementia in an acute hospital setting

Creating Avenues for Relative Empowerment (CARE) in the USA is a programme aimed at improving outcomes for hospitalised older people with cognitive impairment and their families (Li et al., 2003). The programme involved a randomized control trial where one group of families were invited to play an active role during the hospitalisation of their relative, through a family caregiver-focused intervention program which involved nurse family member goal setting, while the control group were only given information about hospital services and policies. The participants in the intervention group had fewer incidents of acute confusion and there was a strengthening of family caregivers' own beliefs about their understanding of older persons' behaviour and their ability to care for them.

## 6.8 End-of-life care services in general hospitals

Many people with dementia will die in hospital. McCarthy et al. (1997) report that about two-thirds of people with dementia spend part of their last year of life in hospital. Research has shown that over three times as many people with dementia die during hospital admission compared to similar people without dementia (Sampson et al., 2009). The provision of end-of-life care to people with dementia is, therefore, pertinent to all care settings not least the hospital care settings. Sampson et al. (2006) demonstrated that, in UK hospitals, people with dementia receive less palliative care compared with similar individuals without dementia. A retrospective case note study conducted in Ireland found that hospital patients with end-stage dementia were significantly less likely than patients cognitively intact to be referred to palliative care intervention (Afzal et al., 2010). In order to deliver better end-of-life care to people with dementia, health care professionals in hospitals need to be more conscious of palliative care frameworks. While guidelines have been drafted to assist nursing homes develop policies and practices in end-of-life care for residents with dementia (Cahill, Doran and Watson, 2010), no such guidelines for acute hospitals exist. The ASI has identified the need to explore, with key stakeholders, the potential for a dementia-friendly hospitals programme, along similar lines to the IHF Hospice Friendly Hospitals Programme (MacConville, 2011).

## 6.9 Best practice

The acute general hospital is not a designated dementia care setting and, as mentioned earlier, is not designed to care for people with dementia. However, dementia care is frequently provided there. Nolan (2007) concluded that 'environmental constraints and multiple demands on nurses' time clearly make meeting the needs of people with dementia in the acute setting difficult', but that quality care can be achieved even with limited resources. Thompson et al. (2010: 306) points out that: 'essentially, good hospital care mirrors good dementia care'. The prerequisites for good dementia care in a general hospital setting include (i) recognising dementia; (ii) timely diagnosis and treatment; (iii) awareness of potentially complicating factors (such as delirium); (iv) preventing agitation; and (v) thorough discharge planning.

Moyle et al. (2008) present a review of the literature reporting on best practice principles for the care of people with dementia in the acute care setting. They identify a number of themes offering a lens for the development of guidelines addressing the unique needs of people with dementia undergoing treatment for co-morbidities in the acute care setting. These themes along with others emerging from the literature are as follows:

- › preventing or delaying hospital admission through augmenting and improving community supports
- › early detection and assessment of dementia (and delirium) in hospital
- › reduction in stressors (both external and internal stressors)
- › up-skilling nursing staff both in knowledge base and attitudes
- › focused communication
- › familiarity that includes family and carer involvement
- › early discharge planning
- › multidisciplinary approach

## 6.10 Approaches to hospital care for patients with dementia in other countries

- › Hospital admissions can result in a broad range of adverse outcomes for people with dementia including higher morbidity and mortality rates, increased length of stay in hospital and increased risk of discharge to institutional care. Best practice entails the provision of well coordinated primary health and social care services in order to avoid the unnecessary admission of people with dementia to hospitals.
- › Outreach and community-based specialist dementia services reduce the use of hospitals by people with dementia, leading to improved patient outcomes.
- › Once admitted to hospital, policies about good dementia care in acute care settings will result in better ownership and leadership of dementia to be adopted and better quality of care for the vulnerable patient. To enhance care, the patient's diagnosis of dementia needs to be communicated to all hospital staff.
- › Given that about one quarter of all patients admitted to acute care settings have a dementia, hospital environments need to be customised to be more dementia-friendly. This will involve action based on the principles and features of good design for dementia care and taking due consideration to features including noise, privacy and layout.
- › Every staff member employed in a hospital should receive specialist dementia training. Ongoing as opposed to once-off training programmes are necessary to ensure that staff can identify dementia among patients and are equipped with the necessary skills to deliver high quality care, including the ability to refer patients to more appropriate service providers and settings as required.
- › A holistic person-centred approach is critical to caring for patients with dementia in acute care settings.
- › The development of a Dementia Champions Programme in acute hospitals facilitates a more person-centred approach to care and helps to raise awareness of the challenge of dementia.
- › Best practice in dementia care also entails assisting people with dementia to maintain or regain their skills and independence following hospital admission in order to reduce hospital discharge to nursing homes. This involves working directly with family caregivers and primary care providers to reduce admissions in the first place and to facilitate a swift return to community-based accommodation.
- › The importance of specific palliative care programmes for people with dementia should be recognised through support for continued and deepened joint action between the IHF and the ASI.

- There is a need to develop better hospital patient information systems yielding data that will more accurately reflect admissions, re-admissions, lengths of stay, and discharges of people with dementia in acute care than is currently possible through the HIPE. While this is challenging, particularly given the under-recording of dementia as a secondary cause of admission, it is nonetheless critically important for service development and for good patient care.

## 6.11 Summary and conclusion

Inevitably, some people with dementia will need to attend A&E departments in acute general hospitals, or be admitted as in-patients to these hospitals. We currently have inadequate information on the number of people with dementia in acute general hospital settings in Ireland. However, those who are admitted to hospitals tend to have poorer outcomes, e.g. longer lengths of stay, than those without dementia. Many countries including England, Scotland, Northern Ireland, Norway and Australia are making great efforts to improve care services for people with dementia in general hospital settings. The Scottish National Dementia Strategy is particularly notable. Our review has identified key areas where improvements are needed so as to transform the care experience of people with dementia in general hospital settings. These include improvements in primary care services, expansion of community care services, early detection and assessment of dementia (and delirium) while in hospital, greater dementia awareness and training among all hospital staff, better person-centred communication strategies that directly involve family caregivers, a reduction of internal and external stressors, and early discharge planning focused on returning the person with dementia to their own home.







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# CHAPTER 7

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## LONG-STAY RESIDENTIAL CARE SERVICES

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In many ways the principle for residential facilities of this type is ... 'small is beautiful'. That is, residential units are set up to accommodate six to eight residents, and patients with dementia are offered the chance to participate in ordinary everyday activities.

*Engedal, 2004*

”

# CHAPTER 7

## Long-stay residential care services

### 7.1 Introduction

As stated earlier (Chapter 4), current government policy focuses on the importance of community care for as long as possible for all dependent older people in Ireland including those with Alzheimer's disease and the associated dementias. However there may come a time in the course of the individual's journey through dementia, where for whatever reason (increase in severity of dementia, other chronic age-related illnesses, acceleration of challenging behaviours, illness of family caregiver, safety issues or inappropriate accommodation) long-term care needs to be considered. In Ireland, few alternatives to the nursing home model of care exist, for older people with dementia who are unable to remain in their own homes. In this regard, the Irish situation contrasts strongly with that in the US, UK, Australia, and other European countries where a range of alternate models to nursing home care including (i) housing with care; (ii) sheltered housing; (iii) hostels; and (iv) specialist care units are now fully integrated components of the long-term care landscape for people with a dementia. For example, in the Netherlands, there are now some 454 small-scale group-housing living facilities across the country and the number is increasing (de Lange et al., 2011). In Ireland, however, only a very small number of housing with care schemes exist, providing accommodation specifically to address the complex needs of people with dementia and none of these are run by a public sector body. Accordingly, when older people with dementia need to move from home into long-term care in Ireland, there are very few alternatives outside of residential care settings available to them.

In Ireland, long-stay care comprises a mix of public, voluntary and private providers. While government policy is committed to maintaining publicly provided long-stay facilities for older people, including those with dementia, there is a shortfall of public beds, while the provision of public community units for older people has for the most part not been realised. Curiously, since the commencement of the NHSS,<sup>44</sup> the proportion of public nursing home beds has decreased significantly and today private beds dominate the long-term care sector. Traditionally, public beds tended to be occupied by people with more serious chronic health problems as they were heavily dependent and had access to more intensive nursing care and to health service professionals including physiotherapists, speech and language therapists, occupational therapists and social workers. This pattern has changed more recently with the reduction in numbers of public beds, the introduction of a common regulatory framework and greater choice and flexibility brought about by the NHSS. As noted in Chapter 3, by far the majority of people with dementia in long-stay care are currently residing in private facilities.

### 7.2 Long-stay facilities in Ireland

The difficulties associated with estimating the numbers of people with dementia in long-stay care facilities have already been deliberated in Chapter 2. Written more than 10 years ago, *An Action Plan on Dementia* (O'Shea and O'Reilly, 1999) pointed to the challenges in planning care services for people with dementia in residential settings in the absence of accurate nursing home population estimates. But, despite calls for a national dementia audit of nursing homes and the authors recommendation that 'this deficiency in data collection needs to be resolved immediately though a careful audit of dementia in long-stay care settings', no action has taken place to date and the issue continues to remain unresolved today.

Attempting to estimate the numbers of people with dementia in long-stay facilities is not helped by the fact that there are multiple sources of information available on the number and type of long-stay facilities in the country. By law, all public, private and voluntary long-stay facilities are required to register with HIQA. While registered facilities are listed alphabetically on HIQA's website, summary information on numbers or types of registered facilities are not provided,

<sup>44</sup> Also referred to as the Fair Deal.

nor is information available on the number of dementia-specific units or specialist care units there are around the country, or indeed the number of people with dementia accommodated within. The provision of public nursing homes beds is monitored via the National Register of Public and Voluntary Units and Beds (referred to hereafter as the National Register), which is up-dated on a monthly basis. The National Register does not provide data on the number of public beds occupied by people with dementia, diagnosed or otherwise. Information on the number of private (for-profit and not-for-profit) nursing homes can be gleaned from NHI. Information collected by NHI includes data on the number of people with dementia in private facilities. Drawing on both the National Register data and NHI data, it can be estimated that there were circa 598 nursing homes in Ireland in 2010,<sup>45</sup> the majority (almost 75%) of which are private and voluntary nursing homes. This is slightly lower than the number of facilities (629) currently registered with HIQA,<sup>46</sup> although this can be accounted for by ongoing attrition as facilities may have closed (and indeed opened) in the interim, for a variety of reasons.

### 7.3 Admission, access and transition to long-stay facilities

There are a whole range of reasons (medical, social, psychological, and economic) why older people (including those with dementia) move to live in nursing homes. The oldest-old, i.e. those aged 85 and over, are, for example, very likely to have gathered a suite of illnesses/disabilities throughout their life-course and quite a few may experience more than one kind of difficulty prompting admission to long-stay care (Fossey, 2008). The problems that lead to the discontinuation of home care and the difficulties that prompt the transition of people with dementia into residential care have been the focus of much research enquiry.

For example, a study conducted by Banerjee et al. (2003) in the UK found that over a one-year period having a co-resident caregiver made admission to residential care twenty times less likely for a person with dementia, thus emphasising the pivotal role played by family caregivers. Higher frequency and intensity of challenging behaviours in the person with dementia was also associated with the transition into residential care in this study. In a different study, the severity of dementia was identified as a key predictor of institutionalization (Moïse et al., 2004). Earlier Australian research has shown that caregiver burden, challenging behaviours, a decline in caregiver and care-receiver health were the key factors precipitating nursing home admission for people with dementia originally being cared for at home by a family member (Cahill, 1997). This same study also showed somewhat ironically that residential respite - a service usually used to delay institutional care - often sped up the process of nursing home admission, as during respite, professional care staff became aware of the excessive and impossible level of care required (Cahill, 1997).

A more recent Australian study showed that even in cases where home care was recommended there was an increased likelihood of an older person being admitted into permanent residential care, within twelve weeks of take-up of residential respite care, if the person had dementia or had no family caregiver (AIHW, 2010). Recent research commissioned by the ASI in Ireland has shown that the key factors influencing family caregivers' decision to move their relatives with dementia into residential care are complex and interrelated. In this small-scale qualitative study, reasons for choosing placement included the excessive demands of caring; a decline in physical and mental health of both the carer and the person with dementia; lack of formal and informal support; conflicting roles and responsibilities, especially for adult children carers; and independent financial means (Argyle et al., 2010). In this study, the decision to place was rarely made alone and was frequently facilitated by professional involvement.

<sup>45</sup> This is based on a combination of an NHI estimate of 447 private nursing homes in Ireland in 2010 (NHI, 2010: 3, 59-70) and the National Register, which shows that there were 151 public and voluntary residential care units in Ireland at the 30 September 2010. According to the Department of Health, there are currently 121 public residential care facilities in operation (Communication from the Department of Health, 12 December 2011).

<sup>46</sup> Registered nursing homes are listed alphabetically on HIQA's website and it is possible to use that information to count the number of nursing homes registered with HIQA at any one time. At 26 October 2011, there were 629 registered nursing homes listed, a small number of which are closed and no longer in operation.

108 For Irish family caregivers, accessing long-term care for a relative with Alzheimer's disease or an associated dementia is not easy. In the absence of community-based social workers, case managers or aged care assessment teams, many people have no idea who to turn to for advice about finding an appropriate dementia-friendly nursing home; nor are they by and large aware of practical issues including wait-listing protocols for nursing homes, assessment procedures and the cost of nursing home care. A recent Irish study has highlighted that access to residential care services specifically for people with dementia tends to be resource-led rather than needs-led (Bobersky and Cahill, 2011) and may involve multiple relocations. The same study has shown how respite care within the same facility eased the transfer of people with dementia into long-term care. There is also widespread belief that some nursing homes often cherry pick their clients and some long-stay care facilities are not willing to admit people with dementia, particularly younger people with dementia. This view was expressed by participants at the National Dementia Summit 2011 who believed that people with dementia are 'getting the door closed in their face' when the diagnosis of dementia is brought up in conversation with certain long-term service providers (ASI, 2011). Further investigation is required to substantiate this widespread belief.

Family caregivers often experience mixed emotions when confronted with the changes arising from their caring "at home", to having their relative cared for "in a home". While relief from the practical physical responsibilities of caring is often enormous and highly valued, some caregivers experience feelings of guilt, loss and isolation, as well as practical and financial concerns (Argyle et al., 2010). It is also well known that caregiving does not cease after a relative with dementia is admitted to long-term care as new caring roles often evolve and many family caregivers continue to maintain close relationships with their relatives and with nursing home staff and continue to provide companionship, practical and emotional support (Cahill, 1997). Indeed, recent research has shown that the 'family' continues to be most salient in the lives of most residents with dementia, and visits from family members are cherished, and deemed to have a very positive effect on quality of life of residents with dementia (Cahill and Diaz-Ponce, 2011). Family members have also expressed a wish to participate in both the care of their relative and the life of the nursing home (Argyle et al., 2010) and it has been shown that facilities with open door visiting policies, where staff are supportive of the family and promote their involvement in the life and culture of nursing homes, and which provide information and education about dementia, all facilitate family members in fulfilling their desired roles (Argyle et al., 2010; Cahill and Diaz-Ponce, 2011).

## 7.4 Quality of care and designing appropriate environments for people with dementia in nursing homes

As mentioned earlier, the vast majority of people with dementia in Ireland living in residential care, are cared for within generic care facilities for older people (see Chapter 3), 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 Alzheimer's disease and the related dementias. This makes the task of providing care to these people for professional care staff often very difficult. As is the case in other countries, concern has been repeatedly expressed about the quality of care for people with different levels of cognitive impairment living in these generic nursing homes (Murphy et al., 2006) and about the very heavy and stressful workload borne by paid staff employed in these types of facilities. Research in several countries and in all types of nursing homes confirms that quality of life for people with dementia is problematic in many residential care settings (Moïse et al., 2004; Hancock et al., 2006).

As mentioned in Chapter 6, people with dementia are particularly sensitive to their psychosocial 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 the facility (Calkins, 1987). Design guidance has long suggested that building configuration may well impact on orientation and social interactions between people with dementia (Day and Calkins, 2002, Day et al., 2000; Poole,

2006; Pynoos and Regnier, 1991) and that the environment can be used as a therapeutic tool in dementia care, thereby compensating for the disability of dementia (Marshall, 1999). Good design models emphasise smallness, domesticity, separate rooms for separate functions, careful use of cueing and signage, noise control, appropriate interior decor including age appropriate furniture and carefully selected colours, appropriate stimulation, a well trained workforce in dementia care, and access to a multi-sensory garden. Good design models also maximise awareness and orientation, maximise safety and security, provide privacy, facilitate optimal stimulation whilst regulating this, offer choice and opportunity for social control, support functional ability, preserve continuity between past and present and facilitates social contact (Lawton, 2000).

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 (Calkins, 2010; Moïse et al., 2004; Brawley, 1997). Whilst the first dementia-specific specially designed care unit planned in Philadelphia in 1965 was described in the literature in the late 1970s, the topic of environmental design and dementia only became an area of great academic interest since the 1980s. Since then, Specialist Care Units (SCUs) for people with dementia have burgeoned in Australia (where they are more commonly known there as “hostels”) and in the Netherlands (where they are commonly known as group-living). SCUs have also been developed or are currently being developed in England, Northern Ireland, Scotland, France, Norway, Sweden, Germany, and the US.

### 7.4.1 What is the evidence base on design and dementia?

While there is growing international support for such SCUs for people with dementia, some commentators call for a stronger evidence base and question whether these facilities are really ‘special’ and whether they provide superior quality care compared to more traditional nursing home units. In response to this, several recent studies have demonstrated the positive effects of SCUs for people with dementia on (i) quality of care; and (ii) quality of life, including improved health, behavioural and functional status; increased autonomy; increased subjective quality of care and quality of life; improved interaction patterns; improved visiting patterns; and increased community access (Cioffi et al., 2007; Morgan et al., 2004; Day et al., 2000; Doody et al., 2001; Sloane et al., 2005).

It is also been suggested that small-scale living makes it easier to provide good dementia care (Marshall, 1999; de Lange et al., 2011). For example, in the Netherlands, Te Boekhorst et al. (2009) in a comparative study investigating the effects for people with dementia of living in small groups homes compared with living in traditional nursing homes, found that for people living in small group homes the beneficial effects include their needing (i) less help with Activities of Daily Living (ADLs); (ii) being more socially engaged; (iii) having a greater sense of aesthetics; (iv) being better occupied; and (v) being prescribed less physical constraints. Interestingly, in this study no difference in cognitive status or and challenging behaviours were found between the two groups of people with dementia living in the two different settings.

Other research which has included the voice of people with dementia has shown that group living homes create structural opportunities for individualised care and focus attention on residents’ personal needs (van Zadelhoff et al., 2011) and that older cognitively intact people resident in nursing homes prefer not to be living in the same environment as people who have a dementia (Murphy et al., 2006). In the Murphy et al. study, older residents involved in Focus Groups commented that they tended to avoid contact with other residents who were cognitively impaired as they found their behaviour at times irritating. At its most extreme, some residents were not merely frustrated by being exposed to others’ challenging behaviours but also reported feeling frightened (Murphy et al., 2006). In the same study, Murphy et al. concluded that people with dementia should be cared for in segregated environments. In a large-scale recently conducted US survey of nursing homes drawing on a national sample, the researchers assessed the status of specialised care for residents of SCUs. Like other studies this work showed some evidence that SCU residents had better health care processes and outcomes (Luo et al., 2010).

## 7.4.2 Irish studies on Specialist Care Units for people with dementia

These international findings are supported by evidence from two recent small-scale yet revealing Irish qualitative studies investigating the effects of SCUs on people with dementia. For example, Myers et al. (2007) found that the relocation from a 'traditional care of the older person ward' to a SCU for a small group of people with dementia had very positive effects. Some residents with dementia regained former skills; their sleep patterns improved resulting in some residents having less need for night-time medication, their functional independence increased and in one case there was a noticeable reduction in challenging behaviour. For health care staff, the SCU allowed them more time to get to know their residents, their life stories and involve them more in activities. The experience for family members was also positive and resulted in more purposeful visits and a decrease in caregiver strain. More recent Irish research investigating the transfer of people with dementia into three different specialist care unit settings (Bobersky and Cahill, 2011) has shown that one month after placement in a SCU, some residents experienced improved mood, increased activity levels and improvements in eating patterns. In the same research, which used a qualitative follow up design, six months after placement, improvements noted by family carers included weight gain, increased levels of alertness, new friendships, and the rekindling of former interests and lifestyle activities (Bobersky and Cahill, 2011). Interestingly, however, it was noted that resident's cognition and mobility continued to decline during the follow up period.

Despite the absence of unequivocal evidence pointing to the value of SCUs - a phenomenon it is argued might be explained by the fact that there are far too many possible design variations to test experimentally and too many different professional groups involved using different methodologies (Lawton, 2000) - the continuing interest in small-scale, home-like facilities in dementia care is significant and across the world SCUs are becoming an increasing feature of the residential long-term care landscape. In the Netherlands, for example, where 25% of nursing home care is currently provided in small-scale, home-like environments, the Dutch government target is for this figure to rise to 33% of all nursing home care to be provided in this way by the year 2015 (de Lange et al., 2011). This programme is backed up by government investment in the area. The French National Plan for Alzheimer and related diseases (2008-2012) provides for both the development of existing SCUs for people with dementia, and the creation of 12,000 new SCU places. In recognition of the different stages of dementia and the different accommodation needs of people diagnosed, a range of different SCUs will be developed in France including units specifically designed to address people manifesting severe challenging behaviours. The French Plan also provides for extra staffing and for the development of a specific training plan for all staff working in SCUs for people with dementia.

## 7.4.3 International consensus on best practice and dementia

Whilst in general it has been argued that this body of literature on design and dementia has tended to be more descriptive than empirical, an international consensus exists on design features and principles for SCUs (Judd, Marshall and Phippen, 1998; Marshall, 1999) (see Boxes 7.1 and 7.2).

### Box 7.1 Best practice in dementia care: International consensus on design features that underpin best practice in dementia care

- > Small scale
- > Familiar, domestic, homely in style
- > Plenty of scope for ordinary activities (unit kitchens, washing lines, garden sheds)
- > Unobtrusive concern for safety
- > Different rooms for different functions
- > Age-appropriate furniture and fittings
- > Safe outside space
- > Single rooms big enough for lots of personal belongings
- > Good signage and multiple cues where possible, e.g. sight, smell, sound
- > Use of objects rather than colour for orientation
- > Enhanced visual access
- > Controlled stimuli, especially noise

### Box 7.2 International consensus on design principles underpinning best practice in dementia care

Design should:

- > compensate for disability
- > maximise independence
- > enhance self-esteem and confidence
- > demonstrate care for staff
- > be orientating and understandable
- > reflect a balance of safety and autonomy
- > reinforce personal identity
- > welcome relatives and the local community
- > allow control of stimuli

Source: Judd, Marshall and Phippen (1998)

In Ireland, although reliable data is absent on the number of SCUs which comply with these best practice guidelines, a growing trend over the last ten years has been the development of SCUs within generic residential care facilities both public and private. In these facilities, people with dementia are cared for in settings where they are separated from other cognitively intact residents. Whilst strident efforts are being made in most of these units to adhere to the aforementioned design principles and features, sometimes it is not always possible due to space restrictions. The upshot is that in some of these SCUs not all residents have their own private en-suite room. Nor are there always separate rooms available for separate functions nor do all such units have immediate access to a safe therapeutic garden. There are also a very small number of stand-alone facilities in Ireland that provide long-term and/or residential respite care exclusively to people with dementia, such as those provided by the ASI and the West of Ireland Alzheimer's Foundation, but these are the exception rather than the norm.

## 7.4.4 Example of Irish best practice in dementia care

Some examples of new models of care provision emerging within both the public and private systems of care in Ireland includes the Teaghlach model, a ‘household’ model of care which was initially developed to drive change in the culture of care from the task-oriented institutional public model to one which supports older people including those with dementia to continue to direct their own lives in a home-like environment supported by consistent and valued teams of health and social care staff. A core feature of the Teaghlach model is to ensure that residential care units become “home-like” in all respects.

The HSE has supported the development of this model of care through capital funding for the renovation of two existing public residential care facilities: (i) St. Joseph’s Hospital, Ardee, Co. Louth; and (ii) Mount Carmel, Clonakilty, Co. Cork which has a SCU for people with dementia. In the private sector, Moore Hall Lodge in Co. Louth, which also contains a SCU for people with dementia, is an example of a private nursing home that has been customised to reflect a ‘household model’ in the delivery of long-stay care provision. Despite these exciting and much needed developments, it needs to be kept in mind that since the overall number of SCUs and standalone facilities in Ireland is so small, only a very small minority of people with dementia requiring long-term care will be able to avail of them. Accordingly, people with dementia in Ireland who are admitted to residential care will generally move into traditional ‘non-specialised’ facilities.

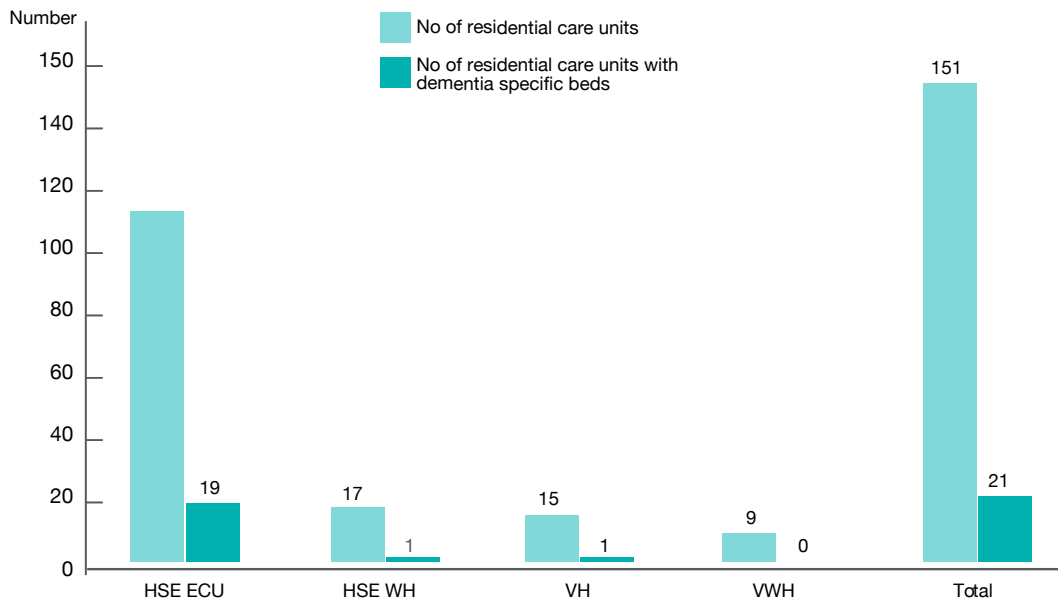
In recognition of the special and complex needs of people with dementia, in 2007 HIQA developed supplementary criteria for dementia-specific residential care settings for older people. These standards we understand are being used during inspections and are being applied to long-stay facilities exclusively designed for people with dementia and nursing homes that care for people with dementia on a physically segregated basis. Amongst several dementia specific requirements, the standards also stipulate that all newly built dementia-specific residential care units are configured in such a way that residents are cared for in groups of no more than ten. However, as far as we are aware, HIQA does not collect information on the number or proportion of registered facilities to which the supplementary criteria apply, making it impossible to know how many facilities in Ireland cater exclusively for people with dementia. This is indeed surprising as HIQA has statutory responsibility for health information, i.e. ‘advising on the collection and sharing of information across the services, evaluating information and publishing information about the delivery and performance of Ireland’s health and social care services’ (HIQA, 2011).

## 7.4.5 Numbers of dedicated dementia-specific beds and numbers of SCUs

While some dedicated dementia-specific beds are available in public long-stay facilities in Ireland, these are still the exception rather than the rule. For example according to the National Register, some 21 (or almost 14%) of the 151 public/voluntary residential care units had dementia-specific beds on the 30 September 2010 (Chart 7.1).



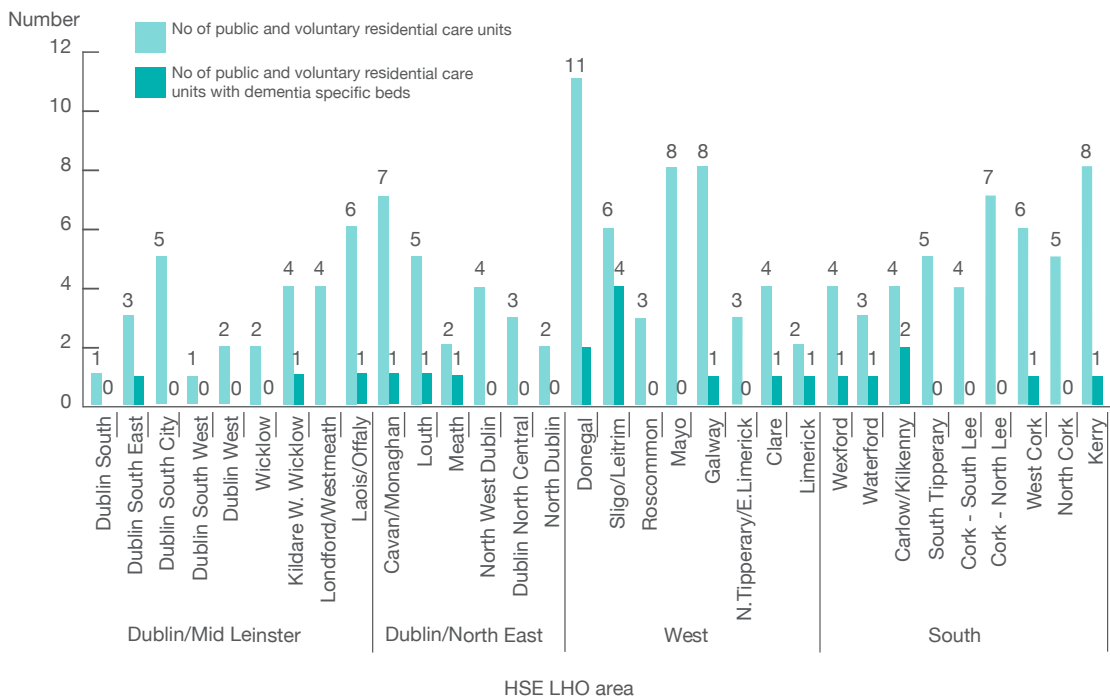
**Chart 7.1** Number of public and voluntary residential care units and number with dementia-specific beds in Ireland by type of facility at 31 September 2010 (n)



Almost all of the 21 residential care units with dementia-specific beds were HSE extended care units (ECU). Further analysis shows that 19 of the residential care units were HSE ECU, and only one was a HSE welfare home (WH) and one was a voluntary home (VH). In total, there were only 373 dementia-specific beds in public facilities in 2010. The average size of dedicated dementia units in public nursing homes was 18 beds.

Chart 7.2 shows the distribution of public and voluntary residential care units by HSE LHO area and with the numbers of the units with dementia-specific beds. Given that there are a total of 21 public and voluntary residential care units in the country with dementia specific beds, it is not surprising that only 16 or one-half of the 32 HSE LHO areas have a public/voluntary residential care unit with dementia-specific beds. Interestingly, whilst some LHOs have no dementia specific beds, three LHO areas (2 in the West and 1 in the South) have more than one public/voluntary residential care unit with dementia-specific beds.

**Chart 7.2** Number of public and voluntary residential care units and number with dementia-specific beds in Ireland at 30 September 2010 by LHO area (n)



**Chart 7.3** Number of dementia-specific beds in public and voluntary residential care units in Ireland at 30 September 2010 by LHO area (n)

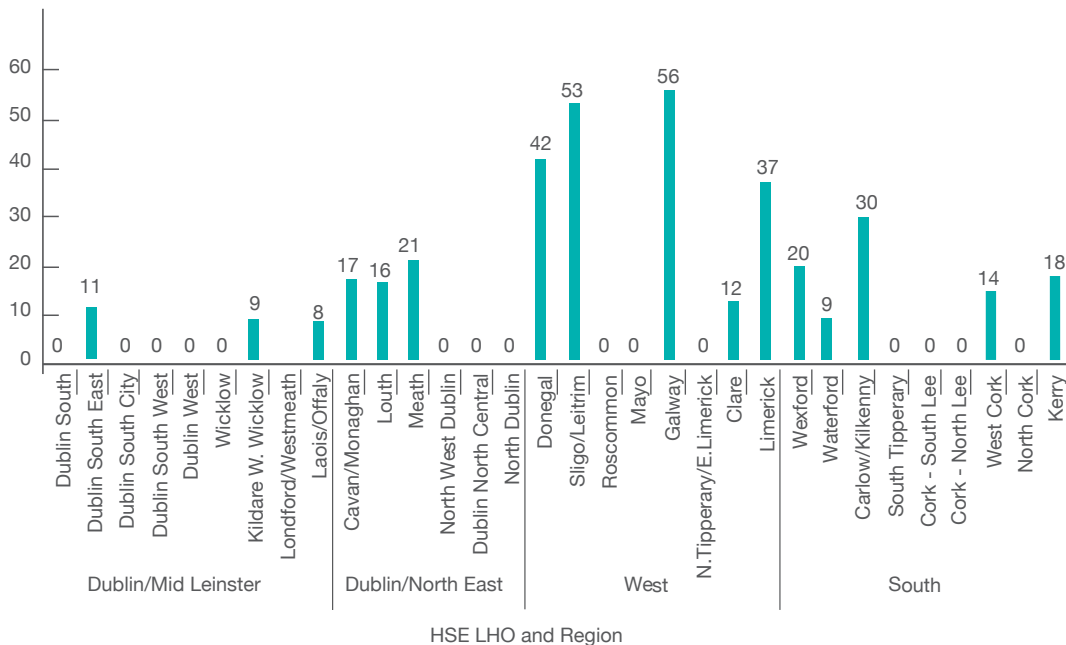


Chart 7.3 shows the number of dementia-specific beds in public and voluntary residential care units in Ireland at 31 September 2010 by the HSE 32 LHO areas. The highest number of dementia-specific beds in public and voluntary residential care units is in three LHO areas in the HSE West, namely, Galway, Sligo/Leitrim, and Donegal.

Information on the availability of dedicated dementia care units in private and voluntary nursing homes can be obtained from the NHI Annual Private Nursing Homes Survey. Although the response rate in this survey was low (34%), the

2009/2010 Annual Survey indicated that almost 21% of private nursing homes provided dedicated dementia care units within their nursing homes. Among these respondent nursing homes with designated dementia units, 97% operated from within facilities with 40 beds or more (NHI, 2010: 28) and the average size of dedicated dementia units in private nursing homes was 19 beds.

This finding is of interest since based on the literature we know that the average number of residents living in SCU in other countries ranges from 5-9 residents in Sweden, the Netherlands and Belgium, to 13-15 residents in countries such as Australia and France (Verbeek et al., 2008). When placed in an international context therefore, the average number of residents with dementia in Irish SCUs both public (18 beds per unit) and private (19 beds per unit) is exceptionally high. It is said that the average size of SCUs for people with dementia may be determined by the interplay of practical considerations such as budget, physical space and staffing (Verbeek et al., 2008). Notwithstanding this, if size alone was used as a defining criterion for SCUs for people with dementia, some of these units would not qualify as a SCU for people with dementia.

### 7.4.6 Data collection systems

In undertaking the research for this report, it has become apparent that there are two systems in place for collecting data on long-stay beds in Ireland, namely (i) the state database of public long-stay facilities compiled and held by the HSE, and (ii) the NHI database based on survey data of private and voluntary long stay beds. Each collects different data for different purposes and presents the data in different ways. For example, whereas the National Register uses Regional/LHO areas to disaggregate data geographically, the NHI survey continues to use the former Health Board areas for disaggregating data by region. Information on the number of dementia-specific facilities and the number and type of dementia-specific units within facilities is, therefore, clearly inadequate. There is no standard definition of what constitutes a SCU in Ireland, nor is there an agreed meaning or definition for the term “dementia specific bed” within a generic facility. The availability of reliable and valid data on the location and quality of SCUs is all the more urgent given the significant concerns about the lack of good, quality specific long-term care facilities for people with dementia expressed by participants at the National Dementia Summit 2011 (ASI, 2011).

As mentioned earlier (see page 112), HIQA (2009) has developed Quality Standards for Residential Care Settings for Older People including Supplementary Standards for residential units offering care specifically to people with dementia and since 2009 has responsibility for the registration and inspection of all long term care facilities offering care to people with dementia. These Standards have placed a much stronger emphasis on the dignity and privacy of individual residents, and on care practices that promote quality of life and quality of care for people diagnosed with Alzheimer’s disease or the related dementias. A full differential diagnosis of dementia is mandatory for admission to SCUs and the latter are required to comply with the principles and features of good practice in dementia care, including the provision of small-scale domestic style dwellings, private bed-rooms, separate rooms for separate functions, staff trained in dementia care, therapeutic gardens, and the appropriate use of signage and cueing.

To summarise this section of the chapter, there is an international consensus about the features and principles of good design for dementia care. There is also some emerging evidence from the international and national literature demonstrating the benefits of small-scale group dwellings both for the person with dementia, their family caregivers and for staff. Our review has shown that in Ireland few people with dementia gain access to specialist care units and even when they do, the size of these units (average of 18 to 19 residents) does not conform with best practice models. We need to develop incentives for people to design more appropriate long-term care alternatives for people with dementia, rather than merely restricting them to accommodation in nursing homes. We can learn from the experience of other countries where National Dementia Strategies have targeted plans for designing more customised purpose-built buildings.

For example, the Norwegian Dementia Plan 2015 has adopted the principle ‘small is beautiful’ in terms of both building size and organisation for residential care settings and states that its Government is committed to designing services on the basis of users’ needs and wishes. Achieving this objective hinges on extra state funding in the form of a new investment grant from the Norwegian State Housing Bank for the construction of nursing homes and community care housing. The French National Plan places an emphasis on adapting the layout and architecture of SCUs for people with dementia who have significant challenging behaviours and a major investment programme has been launched to support this initiative. Specifications for these units are being established by the Minister for Social Affairs along with a range of other statutory and voluntary bodies working in conjunction with professionals who have worked on relevant architectural issues. An Alzheimer’s architecture prize is being created to reward the most innovative nursing homes. The Dutch Dementia Strategy states that ‘a good living environment is essential for people with dementia’ and emphasises the importance of small-scale living. In support of this, the Ministry of Health, Welfare and Sports in the Netherlands is promoting small-scale housing in large-scale settings as well as in local neighbourhoods for people with dementia through government investment of €80million.

## 7.5 Psychosocial interventions

There are a whole range of psychosocial approaches or non-pharmacological interventions that can be used by trained staff to promote well-being and improve quality of life for people with dementia living in residential care. These include: reality orientation, which uses rehearsal and physical prompts to improve cognitive function related to personal orientation; cognitive stimulation therapy, which focuses on information processing; reminiscence therapy, which involves discussion of past experiences and activities individually or in a group; music therapy, aromatherapy, doll therapy, Snoozelins and validation therapy. Many of these approaches have been the subject of extensive systematic reviews and there is emerging evidence demonstrating that several such approaches yield positive outcomes at least in the short-term (Coen et al., 2011; Spector et al., 2000; Spector et al., 2006; Burns et al., 2005; Cohen-Mansfield, 2000; Woods et al., 2005; Neal and Barton Wright, 2003).

Other psychosocial approaches used in long-stay care facilities include pet therapy, creative therapies, structured activity/interaction programmes, and exercise. The latter have also been found to have positive effects (Hokkanen, 2003; Vink and Birks, 2003), as has sensory stimulation programmes (Kovach, 2000). Dementia care mapping, an approach where a trained practitioner spends dedicated time (minimum of 6 hours) in a residential care setting observing and recording instances of well-being and ill-being of residents with dementia, is a further example of a dementia-specific intervention designed to improve quality of care. For over 20 years in Ireland, Sonas aPc has been hosting training workshops focusing on sensory stimulation and communication in both public and private long-stay facilities. A preliminary evaluation of the Sonas method has shown that the intervention may significantly improve quality of life and quality of care in residential and community settings (Hamill and Connors, 2004). Sonas aPc has also developed spirituality programmes for long-stay residents of all faiths.

Although it is beyond the scope of this review to report on or critique in-depth each of these non-pharmacological interventions, it is suffice to say that there is a need for a lot more empirical research to be undertaken in Ireland on these psychosocial approaches. As far as we are aware there is only one major RCT being conducted in Ireland (led by NUIG) evaluating Reminiscence therapy for people with dementia in public and private long-stay care facilities in the West (O’Shea et al., 2011). More empirical research of this nature would undoubtedly help to create an evidence base in Ireland to further transform practice and improve quality of care.

## 7.6 HIQA dementia specific supplementary standards

There is no way of knowing the extent to which some, or all, of these psychosocial programmes are available at any given time in long-stay facilities in Ireland, but certainly since the establishment of HIQA and the development of residential care standards, a much greater focus is currently being placed on quality of life and quality of care

issues within residential care settings and an emphasis on enabling residents (including those with dementia) to live full and enriching lives that reflect as best as possible the lives they led prior to their admission to long-term care. The HIQA dementia-specific Supplementary Standards, for example, stipulate that staff are trained in and understand the communication needs of residents with dementia and are trained and make every effort to support and facilitate resident's verbal and non-verbal needs in an individualised manner. There is recognition within these Standards that people with dementia need additional time in order to deliver truly person-centred care. Person-centred communication is encouraged in all interactions in consultation with relevant health care professionals.

These HIQA Standards also stipulate that residential care units caring for people with dementia actively use personal items, appropriate therapies and promote quality of life, and that facilities provide evidence, where appropriate, that techniques such as life stories, reminiscence, reality orientation, validation, sensory equipment and music are used to enhance communication. There is also reference within the Supplementary Standards to meaningful self-expression taking place in dementia care facilities, which should be facilitated by occupational, recreational, physical and sensory stimulation. Whilst there is no doubt that such psychosocial programmes have acquired more significance in recent years, having been endorsed by HIQA, it is not yet clear the extent to which real improvements in quality of care or indeed quality of life in SCUs has been achieved. Like in other countries, there is some evidence in Ireland demonstrating that people with mild and moderate cognitive impairment living in nursing homes would welcome having many more therapeutic interventions (Cahill and Diaz-Ponce, 2011).

## 7.7 End-of-life care services in long-stay care facilities

Although we do not have accurate information in Ireland on where people with dementia die, it is reasonable to assume that like in other countries, many probably die in nursing homes or in hospitals and therefore long-stay care facilities are important providers of end-of-life care to people with dementia. In one UK study, describing the last twelve months of life of people with dementia, the researchers found that people with dementia (41%) were, compared with cancer patients (9%) more likely to have lived in a nursing or residential home setting for the whole of their last year of life (McCarthy, Addington-Hall and Altmann, 1997). In the US the majority of dementia-related deaths (66.9%) occur in nursing homes (Mitchell et al., 2005). Mitchell et al. (2004a) report that 71% of residents with advanced dementia had died six months after nursing home admission.

Palliative care beds, defined by the Department of Health as those nursing home beds 'allocated to patients at a time when medical expectation is no longer cure' (Department of Health and Children, 2009: 22) are scarce resources in long-stay care in Ireland and, unlike the US, we have no specialist hospices dedicated to the care of people with dying with end stage dementia. As at 31 December 2008, the Long-Stay Activity Statistics report that only 1.1% of all nursing homes beds in Ireland were palliative care (0.9% of these were in long-stay beds and 2.7% were in limited stay beds.) It should be noted that these statistics do not accurately reflect the level of dementia-related deaths that occur in nursing homes, nor do they recognise the care to people with dementia in 'nursing home beds' (not categorised in the statistics as 'palliative care beds') that integrates a palliative care approach. The absence of adequate palliative care beds may be an indication that people with dementia in nursing homes are not seen as being in need of end-of-life care. It may also be that there is a lack of awareness or understanding that a person diagnosed with dementia will die with a dementia, regardless of the primary cause of death (Wilcocks et al., 2008).

People dying from and with a dementia are an especially vulnerable group. Their end-of-life care needs may be further complicated by the cognitive impairment, the prolonged illness trajectory, pain, communication difficulties, challenging behaviours and the absence of staff specially trained in end-of-life care and dementia care issues. It is argued that their end-of-life care should extend beyond symptom control to encompass resident's psychological and spiritual needs (Bayer 2006; Tilley and Fok, 2008) and that there should be a judicious use of medicines, interventions and specialist teams dedicated to enhancing quality of life. However, it is suggested that either too little or too much is usually done for people dying with an advanced dementia (Downs, Small and Froggatt, 2006).

118 Writing from the US, Volicer (1986) advocates for the appropriate management of symptoms such as pain and behaviours and the involvement in programs such as hospices. Robinson in the UK has called for the development of practice guidelines for end-of-life care and dementia and argue that compared with cancer care there is little practical guidance available on the provision of end of life care in dementia (Robinson et al., 2005). Another study from the US paints a rather dismal picture of end-of-life care for people with dementia in nursing homes (Mitchell et al., 2004b). In an Irish study looking at end-of-life care needs and dementia, the issues family members (elderly spouses of the deceased) reported as problematic included poor communication, lack of involvement in key decisions, and a sense that the resident (their relative) was not being treated respectfully as a person or that their symptoms were not being adequately managed. Overall, however, in this same study, bereaved spouses were extremely pleased with the type and level of person-centred care provided by nursing home staff to their dying relatives (Cahill, Doran and Watson, 2011). In the same Irish study, drawing on the experiences of older bereaved spouses whose relatives had died with dementia in nursing homes in both Northern Ireland and Ireland, the authors drafted guidelines, based on research findings and the views of expert health service professionals, to assist nursing homes develop policies and practices regarding the delivery of quality care in end stage dementia.

There are also other excellent examples of palliative care initiatives being developed in Ireland for people with dementia living in residential care settings in Ireland. Two such projects are those supported by the IHF.<sup>47</sup> The first, Dementia and Palliative Care Action Research Project is a two-year project being conducted under the auspices of Clare Mental Health Services for Older People (CMHSOP). It aims to devise, implement and evaluate appropriate palliative care responses for people with dementia living in a residential care setting. The second project, the Planning for the Future Project, based at St Vincent's Hospital in Athy (Co. Kildare), aims to support staff in their discussions with residents living in a dementia-specific unit (Le Cheile) and their family members about advance care planning and with end-of-life issues.

### Box 7.3 Example of best practice: Beyond Barriers, An Alzheimer Scotland Partnership Project Scotland

In Scotland, *Beyond Barriers*, An Alzheimer Scotland Partnership Project, funded by the Scottish Government and delivered by Alzheimer Scotland between 2007 and 2009, set out to develop current care practice in nursing homes across Scotland by supporting both staff and relatives to meet the palliative care needs of people at end stage dementia. The project provided an innovative educational programme involving staff and family members of residents with dementia together. Communication with the person with dementia was a focus as was staff support to improve practice through action learning. The project was piloted and rolled out in more than 50 nursing homes across Scotland. The evaluation of the initiative demonstrated improved outcomes including: (i) improved staff understanding of relatives' needs, (ii) an increase in relatives' trust of staff, (iii) improved communication between staff and relatives with the person with dementia, (iv) an improved understanding of residents' spiritual needs by staff and relatives, (v) improved quality of life of relatives, (vi) a better understanding of end of life care and advance planning, (vii) improvements in pain management and (viii) opportunities for staff to share learning with colleagues (Alzheimer Scotland, 2009). The project also resulted in the development of a new training resource, which has been accredited by the Scottish Qualification Authority.

<sup>47</sup> These projects form part of a wider IHF programme aimed at supporting the introduction of palliative care services to address the individual end-of-life needs of people with dementia in a holistic, person-centred and planned way [See [www.ihf.ie](http://www.ihf.ie)].

## 7.8 Long-stay care facilities of vulnerable groups of people

Younger people with dementia in Ireland find it particularly difficult to access residential care (ASI, 2011) and because of their age, life experiences and interests, even in circumstances where long-term care facilities are accessed, the environment is often far from ideal. In recognition of the apparent gap in residential care services for younger people with dementia, the French Alzheimer Plan has called for a study on the accommodation needs of this particular group and to use the results of the study to inform the development and design of residential care facilities for younger people with Alzheimer's disease.

Current thinking suggests that people with intellectual disability and dementia are best cared for in services with specific intellectual disability expertise. For people with intellectual disability and dementia who can no longer live at home or in supported housing, they may be best accommodated in residential care facilities for people with intellectual disability. Providing care in this type of facility requires consideration of the need for increasing specialist health care and eventually end-of-life care as their dementia progresses and ensuring that there is a range of suitable accommodation and appropriate staffing. Some people with intellectual disability and dementia are likely to be accommodated in registered nursing homes intended mainly for older people or specifically people with dementia. It must be remembered that where people with learning disabilities access services for older people they are often 20 years younger than most of the other residents.

## 7.9 Staff knowledge and skills

It is important that people with dementia living in nursing homes are cared for by trained staff who have excellent dementia skills and gerontological education. It is equally as important that the entire workforce employed in these settings receive the support and training needed to ensure that they do not suffer from physical and mental exhaustion (burn out) and can adopt as best as possible a positive attitude in their daily work. Dementia care is not easy work; it can be both physically and emotionally draining for paid care staff who apart from the hard physical labour of caregiving often develop very close affectionate bonds and relationships with their residents. In the absence of appropriate training, many staff employed in the area find the work very stressful and challenging and, indeed, many worry excessively after hours about the ethical and moral dilemmas they encounter in their day-to-day work. Training and the use of a good mentor system in nursing homes would greatly support these front-line practitioners.

Murphy et al. (2006) found that many nursing home staff reported that they lacked the skills to manage residents with dementia. A more recent survey of nursing home care staff found that relatively few nurses (26%) and even fewer care attendants (17%) in residential care in Ireland had received dementia training. Nevertheless, Cahill, Doran and Watson (2011) found that the caring attitudes of nursing home staff and their professionalism were highly valued by spouses of residents with dementia. These findings were in accordance with those reported from a study conducted for the All Ireland Gerontological Nurses Association (AIGNA) where several examples were provided of the caring and clinical roles played by registered nurses in residential care settings and the contribution they make to the lives of people with dementia (Heath, 2010). An Action Plan on Dementia (O'Shea and O'Reilly, 1999) recommended the development of effective training programmes for staff working in all types of residential care facilities and there have been some significant developments in this area. The need for improved and on-going training for staff working with people with dementia in nursing homes continues to be a priority embedded in the dementia specific HIQA standards and has been emphasised in all of the national strategies examined for this research review.

## 7.9.1 Dementia training for health service professionals in Ireland

A major development in this regard has been the establishment since 1999 of the DSIDC, an organisation originally funded by the Department of Health<sup>48</sup> and having responsibility for the provision of multidisciplinary education and training in dementia care to health care professionals across the country. Over the years, through its workshops, extra-mural classes and seminar series the DSIDC has trained thousands of health service professionals. It has produced training videos and a multitude of other relevant training materials and information kits. A more recent and welcome initiative has been the development of a NDEP for nursing staff working within Older Person Services within the HSE with funding from the National Council for the Professional Development of Nursing and Midwifery. The HSE Office of the Nursing and Midwifery Services Director (ONMSD), which has education and training as a key focus of its work, is working in tandem with the HSE Nursing and Midwifery Planning and Development Units, on this programme.

As part of the programme, an Educational and Training Needs Analysis to identify gaps in education and training on dementia to nurses and non-nursing staff working across all Older Persons services was completed in 2009 and findings presented in a report to the National Steering Group in February 2010. One of the key findings from the analysis was the dearth of dementia training amongst nursing staff and care attendants. For example, findings showed that 83% of nurses and 78% of care attendants have received no training in dementia in the past five years. Generic needs identified include recognising signs and symptoms of dementia, understanding the various stages of progression and related behaviours, impact on memory, mood and communication (De Siún and Manning, 2010). As dying with or from a dementia can be particularly challenging for the individual and for those responsible for that person's care, there is also an urgent need for training in end-of-life care (HSE and IHF, 2008).

A key aim of the NDEP has been to design and deliver a suite of education programmes to nursing and support staff working in caring for older people with dementia in acute, residential and community care settings in the Irish health service. The educational programme, designed and peer-reviewed by experts in dementia, including senior staff at the DSICD and the ASI, has been developed and piloted. The findings from the pilot programme indicate that the programme has positively influenced participants' attitudes and knowledge towards dementia. It was officially launched in 2010 and is being rolled out nationally in 2011. The programme will mainly be delivered through the 20 Centres for Nursing and Midwifery Education (CNEs), which provide education and training to nurses across the country.

Many of the National Dementia Strategies in other countries (Northern Ireland, England, France, Scotland and Australia) have targeted programmes for health service professional training and recognise that quality of care for people with dementia in residential care settings can be enhanced through training, knowledge and commitment of staff. The development of explicit leadership in residential care settings is also an objective of the English National Dementia Strategy. The French Plan emphasises the need for specially trained professionals and provides for the creation of the role of 'gerontological assistant' in existing and new SCUs for people with dementia.

## 7.10 Issues arising from the Nursing Home Support Scheme

The NHSS has since October 2009 been the single means of providing public funding to older people, including those with dementia, wishing to enter residential care homes for long-term care in Ireland. It seeks to create equity in state support for people receiving long-term care (including those with dementia) by applying the scheme to HSE-approved public, private and voluntary nursing homes. It is not restricted to older people alone, as anyone

<sup>48</sup> Whilst during the start up period the DSIDC based at St James's Hospital received its core funding from the DOH, funding is now received from the HSE.



who is ordinarily resident in the State and assessed as needing long-term nursing home care can apply for the scheme. Therefore, younger people with dementia are eligible to avail of the NHSS, if they require care in a long-term residential care setting.

The National Treatment Purchase Fund (NTPF) is designated under Section 40 of the Nursing Homes Support Scheme Act 2009 to undertake a process of negotiation and agree payments on the cost of long-term residential care services with approved private and voluntary nursing home owners. Public nursing homes are not required, however, to enter into negotiations with the NTPF. Payments to private nursing facilities are made directly by the HSE to the proprietor at agreed prices. In Australia and in the UK greater financial incentives are given to nursing homes to admit people with dementia, which undoubtedly has implications for the cost of nursing home care. In Ireland, however, the agreed price does not vary according to the care needs of residents of nursing homes. The negotiated prices are based on a standard care package rather than on actual and often very differing care needs of residents. Indeed, the NTPF has no 'cost of care' model/template on which to base their negotiations.

The first step in making an application for state support under the NHSS is submitting a request for a care needs assessment. This application can be made by the person seeking residential care services, who could be a person with dementia, or by another person on behalf of that person. As the legislation currently stands, an application can be made on behalf of a person (including those with dementia) without it ever being discussed with him/her. Upon receipt of an application, an arrangement is made by the HSE for a care needs assessment to be carried out. In the absence of a single care needs assessment tool for people applying for state support under the NHSS, a Common Summary Assessment Report (CSAR) is currently being used to assess the needs of both people requiring home care and those in need of long-term residential care services. Several health professionals may assess eligibility and sometimes a multidisciplinary assessment takes place. The CSAR assesses the cognitive status of the individual and takes into account ADLs, mobility needs, medical requirements and other relevant matters influencing care need. However, the instrument does not allow for distinctions to be made between the specific care needs of different applicants, nor can this instrument be used as a mechanism or basis on which to prioritise funding into dementia care.

After an extensive literature review and much discussion and debate, a consensus was reached that a new single assessment tool, the interRAI, would be piloted in four different care settings (including community, hospital and residential settings) across two different geographical areas in the country. The piloting of this tool is due to be completed in March 2012. This project is being led by senior staff at the HSE and overseen by a NHSS Working Group. Whilst the costs of using this new approach may be considerable (software purchase, payments to interRAI, training manuals and time taken to administer the assessment - up to 90 minutes per person), it is envisaged that if and when adopted, the interRAI assessment tool will significantly improve care planning.

It should also be remembered that the cost of public nursing homes facilities is higher than the agreed prices paid for private nursing home places. However, private nursing homes tend not to provide allied health services, whereas public nursing homes by and large provide a broader range of services. Furthermore, the price charged for care by an approved private nursing home is based on negotiation and agreement between the nursing home qualifying for the scheme and the NTPF. The services falling within the scope of long-term residential care and covered by the published cost/price are:

- > nursing and personal care appropriate to the level of care needs of the person;
- > basic aids and appliances necessary to assist a person with the activities of daily living;
- > bed and board;
- > laundry service.

In practice, however, the range of services covered by the NTPF agreements is quite narrow and excludes costs associated with fundamental care elements such as all therapies, chiropody and social programmes. Many other items which, on the face of it, are services expected to be included as part of long-term nursing home care for residents are also excluded. It would seem that the list of items not covered by the NTPF agreements is growing and includes a range of items required for nursing and personal care as well as basic aids and appliances to assist with ADL. A number of complaints concerning restrictions in what is covered by the NHSS were received by the Ombudsman who is aware of dissatisfaction in this area and has voiced concerns (Office of the Ombudsman, 2010). Accordingly, further clarification is required in relation to the liability of the person availing of state support under the NHSS for any additional charges/fees over and above this specified charge/price. This issue becomes even more complicated when a resident has diminished mental capacity as it may become difficult to establish if that person had actually given consent to receive the service in question, particularly in the absence of an enduring power of attorney, ward of court system and family members.

The NHSS is based on a co-payment between the State and an individual nursing home resident. The resident makes a contribution towards the cost of care and the State pays the balance. The payment by the HSE is called State Support. A financial assessment (which involves an assessment of all of the applicant's income and assets; their material wealth) is used to determine the contribution that the older people will make towards their care and the corresponding level of financial assistance to be provided by the state. Where an applicant's assets include land and property in the State, the contribution based on such assets may be deferred and collected from the person's estate. In other words, it does not have to be paid during a person's lifetime. This is an optional Nursing Home Loan element of the scheme, which is legally referred to as "Ancillary State Support". One concern that has been expressed is that the financial assessment of the NHSS does not take account of the financial circumstances of families of younger people with chronic illness where there is a mortgage to be paid and ordinary household expenses to be met (Office of the Ombudsman, 2010). The Ombudsman has also expressed concern that there is no legal entitlement to financial support for nursing home care and it is dependent on available resources:

The NHSS model is ... based on the principle that responsibility for nursing home care rests primarily with the patient and/or family; the State may support the patient/family financially but this is subject to the availability of resources and to the individual satisfying a means test. Support under the NHSS is not guaranteed and the Scheme is not demand-led. If demand outstrips the availability of resources then the applicant may be placed on a waiting list until such time as resources become available (Office of the Ombudsman, 2010).

These issues are outside the scope of this review, but will have major implications for people with dementia requiring nursing home care in the future. Moreover, while the NHSS has succeeded in bringing greater equity to state support for older people receiving long-term care across public, private and voluntary nursing homes, concern has been expressed that the new system for financing nursing home care may channel funding away from home care services (Ahern et al., 2007). The scheme has also led to concerns being expressed about the Department's intention as to its future involvement in the direct provision of nursing home care (Office of the Ombudsman, 2010) as public bed numbers continue to fall.

## 7.11 Approaches in other countries

- › A range of alternate models to nursing home care for people with dementia exists in other countries such as the Netherlands, Australia, France, Norway, Sweden and the US. These options include (i) housing with care, (ii) sheltered housing, (iii) hostels and (iv) specialist care units (v) group-living and (vi) nursing home care.

- > International evidence points to the wisdom of providing care for people with dementia in small-scale, homely and specialised care settings.
- > The size of SCUs in other countries ranges from 5-9 residents in Sweden, the Netherlands and Belgium, to 13-15 residents in countries such as Australia and France.
- > The French National Plan for Alzheimer and related diseases (2008-2012) provides for both the development of existing specialist care units for people with dementia, and the creation of 12,000 new places in SCUs.
- > The Dutch Dementia Strategy states that ‘a good living environment is essential for people with dementia’ and emphasising the importance of small-scale living. In support of this, the Ministry of Health, Welfare and Sports in the Netherlands is promoting small-scale housing in large-scale settings as well as in local neighbourhoods for people with dementia through government investment of €80million.
- > Hospices for people dying with dementia as is the case in the US.
- > Scottish Beyond Barriers - a program designed to develop current practices and meet the palliative care needs of people with a dementia.
- > Innovation and evaluation of psychosocial interventions for older people with dementia in long-stay care facilitated through incentive schemes and innovation awards schemes at local level.
- > Appointing local champions for people with dementia would assist in maintaining the visibility of older people with dementia, whether living at home or in residential care facilities.

## 7.12 Summary and conclusion

The complex accommodation needs of people with dementia in long-stay care in Ireland has been the main focus of this chapter in which we have argued that in Ireland few alternatives exist to nursing home care for older people with a cognitive impairment who are unable to remain living at home in the community. Unfortunately hard data on exact numbers of people with dementia in long stay settings is largely absent, including data on the number and type of dementia-specific accommodation that is available. Our analysis leads us to conclude that there appears to be very few dementia-specific beds available across the country in the 151 public and voluntary residential care units operating under the auspices of the HSE and only 21 facilities in 16 of the 32 HSE LHO areas offer such accommodation.

Where accommodation is available the average size of dedicated dementia units provided through the HSE is 18 beds. Preliminary data from the private sector (NHI survey) suggest that one in five private nursing homes has a dementia unit and that the average bed occupancy in these private units is 19. When placed in an international context, therefore, our findings show that the average number of residents with dementia in Irish SCUs both public and private is exceptionally high. Through a perusal of the available data it is concluded that dementia remains an under-resourced and hugely under-prioritised health condition in Ireland. International evidence points to the wisdom of providing care to people with dementia in small-scale, homely and specialist care settings and recent HSE initiatives like the Teaghlach model need to be evaluated and further promoted.

124 This review has led us to conclude that definitions and classifications of different types of nursing homes used in the Long Stay Activity Report and the National Register on Public and Voluntary beds are anachronistic and are not fit for purpose. They need to be revised to reflect the considerable changes in residential care provision in Ireland in recent years. HIQA needs to provide summary statistics on people with dementia including severity in all registered long-stay facilities as well as establishing a register of specialist dementia nursing homes and special care units for people with dementia within nursing homes. HIQA also needs to make available information on inspections that have been undertaken using the dementia-specific supplementary care standards. There is also a need for new, integrated and multidisciplinary dementia skills and knowledge programmes to guide formal training and education of staff working with people with dementia in residential care settings. This should be provided on a uniform and national basis and linked to ongoing and existing education and training structures.

There are a whole range of psychosocial approaches or non-pharmacological interventions that can be used by trained staff to promote well-being and improve quality of life for people with dementia living in residential care. These include reality orientation, cognitive stimulation therapy, reminiscence therapy, aromatherapy, music therapy, and validation therapy. Most of these approaches have been the subject of extensive systematic reviews and there is emerging evidence demonstrating that several such approaches yield positive (at least in the short-term) outcomes. We need to collect more information about which of these therapies are being used in dementia care settings in Ireland. We also need more local Irish-based research evaluating these therapeutic interventions.

Finally, in the context of residential care for older people in Ireland including those with a dementia, this review has shed light on the fact that several important and very welcome policy changes designed to promote equity and access and improve the quality of life for people with a cognitive impairment living in nursing homes have occurred in recent years. Such major policy changes include the introduction of the nursing home support scheme, the establishment of HIQA, the publication of nursing home standards including those for SCUs and the publication of restraint policies by the Department of Health (2011b) for older people living in designated long-term care facilities. No doubt these policy initiatives will help in no small way to enhance and enrich the everyday life of older people with dementia living in long-stay care in Ireland.

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Photo: Ken Finegan

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# CHAPTER 8

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## CONCLUSION

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The key to this new era of dementia care must be informing, inspiring, educating and training the diverse workforce that delivers care and services to people with dementia and their carers.

*Hunt in Downs and Bowers, 2008: xxi*

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# CHAPTER 8

## Conclusion

Dementia has not yet permeated into the minds of the public or policymakers when it comes to priority-setting and the allocation of scarce public resources. It is a relatively new area of policy focus, not only here in Ireland but worldwide. That is now changing, as commensurate with population ageing, the number of people with dementia is rising in almost all developed countries. Concern about increasing numbers with the disease has been matched by fears about the impact of the disease on costs and budgets. By way of a response, more and more countries have now developed action plans and strategies to support investment in infrastructure, administrative systems and services for people with dementia. The various plans that are now available are relatively consistent and convergent with respect to what needs to be done with a common emphasis on: primary prevention, changing private and public attitudes to the disease, diagnosis, training and education, care pathways, best practice, innovation, research and policy implementation. Dementia, however, continues to lag behind other chronic diseases in terms of budget allocation in most countries, and in the share of resources devoted to research on the topic, particularly relative to disease burden.

Currently, the number of people with dementia in Ireland is just over 40,000, with numbers expected to treble over the next 30 years as population ageing continues in the country. Dementia has, however, a relatively low impact factor when it comes to public funding in Ireland, which is surprising given that the incidence of the disease is higher than cancer and heart disease, both of which figure prominently in public health care budgets. Not surprisingly, therefore, the system of care for people with dementia in Ireland is currently unsustainable due to funding weaknesses, the absence of dementia specific services and an over-reliance on family carers who carry a disproportionate burden of the care responsibility in the absence of a comprehensive and integrated public response. The recent government promise of a new National Dementia Strategy for Ireland by 2013 is, therefore, both opportune and timely, given the small window of opportunity available before both the numbers with the disease and the cost to the exchequer reach crisis proportions. If ever there was a time to make a difference now is that time.

This study is part of a data gathering exercise to inform the development of the Irish Strategy on dementia which will be developed by the Department of Health over the next year. The objectives of this evidence-based research review, as agreed between the funders (AP), the Department of Health and the contract researchers, were fourfold:

1. to review current and future demographic trends in Ireland and provide estimates of current and future dementia prevalence rates, in relation to both those aged 65 and over and younger people;
2. to specify the main economic costs of dementia care;
3. to review current service availability (based on the recent HSE audit) and estimated future demand for services;
4. to review best practice in dementia care locally and internationally.

There are, therefore, many areas excluded from the current analysis because they fall outside the terms of reference of the study. One of the obvious omissions is any consideration of advocacy, including the role of people with dementia in planning for their own care. There is a great ethical challenge in dementia care since the disease itself influences the person's capacity to advocate for their own interests. This raises the possibility of policy and practice being developed by proxy, in the interests of people with dementia but without their voice. A person-centred approach would facilitate people with dementia having their voices heard in relation to their own care but would also facilitate their involvement in policy formulation and implementation. This is now possible due to improvements in the diagnostic process which for many people is happening at an earlier stage in the condition.

The involvement of people with dementia, while not possible in our research, should, therefore, be a core element in the next stage of the development of the new Strategy. This will be a challenge for the future direction of dementia care in Ireland, and indeed in all countries, irrespective of how services are organised and financed. The challenge will have to be faced, however, if people with dementia are to play a central role in the planning and delivery of their own care. Having older people with dementia involved in the development of new models of care would make it more likely that the principles articulated at the beginning of this report namely: person-centred care, comprehensiveness of provision, home care bias and access to services on the basis of need, will be reflected in the new Strategy.

Prevalence of dementia increases almost exponentially with age, nearly doubling every five years from the age of 65 years onwards. While there have been no comprehensive prevalence studies on dementia carried out in Ireland, the application of EuroCoDe age/gender specific dementia prevalence rates to the 2006 Census of Population in Ireland suggests that there are currently 41,740 people with dementia in the country. An estimated 3,583 of these people (approximately 8.6% of all people with dementia) have early onset dementia and most of these are likely to be men. Our best estimates, albeit extrapolated from a number of uncertain sources, suggest that there are approximately 700 people in Ireland with Down syndrome and dementia. Both early-onset dementia and dementia within Down syndrome populations present difficulties for service providers since they occur in younger age cohorts who do not fit easily into care structures and processes designed for much older people. A major task for the new Strategy will be to develop appropriate services for both these groups in familiar settings that recognise their particular needs.

There is regional variation in estimated dementia prevalence rates across Ireland; LHO areas in the HSE West region have the highest prevalence rates of dementia with each of the nine areas estimated to have at least 1% of its total population living with dementia; Roscommon has the highest share of people with dementia in the population at 1.40 per cent. Eastern counties tend to have the lowest share of the population with dementia, with Dublin West having the lowest share at 0.63 per cent. Even in such a small country as Ireland there are clear regional differences in prevalence rates for dementia, reflecting unbalanced age distributions across the country, underlining the importance of age structure for prevalence estimates and service delivery. Just looking at the age structure of local populations can tell you a lot about the potential prevalence of dementia in that area and the need to structure services accordingly.

The major increase in the number of people with dementia in the country is likely to occur after the year 2021, with the numbers growing to between 141,000 and 147,000 by 2041, depending on assumptions about migration and fertility. In line with the projected growth in the number of the oldest old population, the most marked increase in the numbers with dementia will be amongst people aged 85 years and over. The importance of having a National Dementia Strategy in place and embedded before such huge growth in the numbers of people with dementia is evident from the data generated for this study.

Calculating incidence of dementia is even more problematic than calculating prevalence. Incidence refers to the number of new occurrences of the disease in the population over a period of time. Dementia is difficult to recognise, as people often confuse the symptoms of dementia with the signs of normal ageing. However, more cases are now being detected at earlier stages, due to improvements in primary and community care diagnostic and assessment services and increased public awareness about the disease. Incidence rates are also rising because more and more people are living to the age when dementia usually strikes. Using a Delphi consensus study, Ferri et al. (2005) have estimated an incidence rate in Western Europe of 8.8 new cases per 1,000 persons over 60 years of age per year. A tentative extrapolation of lower middle-range international incidence rates to the elderly population in Ireland suggests that approximately 4,000 new cases arise in the general Irish population every year (O'Shea, 2007).

There is no reliable official data on the number of people with dementia in the country, or where these people are likely to be located. Our calculations suggest that there are 26,104 people with dementia living at home in the community; most of these do not have a formal diagnosis, many are not aware that they have the disease and few are likely to be in contact with the health and social care system. An estimated 14,266 people with dementia live in various public,

private and voluntary long-stay facilities across the country, including 537 people aged less than 65 years. Our estimate of the number of people with dementia in long-stay facilities suggests that 63% of all long-stay residents have dementia. This is significantly higher than the official estimate of the Department of Health (Department of Health and Children, 2009), which suggests that only 26% of people in longstay units have dementia. However, the latter is generally recognised as an underestimate and our calculation, for all its imperfections, is more in line with international evidence, which suggests that between 60% and 70% of long-stay residents have dementia. The remaining people with dementia are likely to be found in acute care settings or in mental health facilities.

This study has estimated the overall cost of dementia in Ireland to be just over €1.69 billion per annum, 48% of which is attributable to an opportunity cost valuation of informal care provided by family and friends to those living with dementia in the community. A further 43% is accounted for by residential long-stay care, while formal health and social care services contribute only 9% to the total costs of dementia. The average cost per person with dementia in Ireland is estimated at €40,500, which is consistent with per capita estimates from other countries. Valuing caregivers at the replacement average wage rate for a care assistant would double the overall cost of dementia in Ireland. Including people in acute care with a secondary diagnosis of dementia also raises costs significantly. Although relatively few cost of illness studies have been carried out in Ireland, making it difficult to compare the economic cost of dementia with other conditions or diseases, the limited evidence that is available suggests that dementia is associated with a relatively high economic burden. This has been confirmed in a UK analysis which, using a similar methodology to cost a number of conditions, reported that the economic and social costs of dementia were almost double that for cancer and treble that for heart disease. If that result holds for Ireland then public expenditure on dementia needs to increase to reflect relative burden of care. At the moment, we do not have any official published data on public expenditure on older people with dementia in this country to allow comparison with other vulnerable groups or diseases. The generation of this data should be a priority in the development of any new Strategy for older people.

Diagnosis is critical to the initiation and development of appropriate pathways to care in dementia. For that reason, the National Dementia Strategy in England has a clear vision to 'make early diagnosis and treatment the rule rather than the exception'. In France, there is now a network of 400 memory clinics, which allows consistency in diagnosis in less than 50 days. In Ireland, early diagnosis, and sometimes any diagnosis, is the exception rather than the rule. Even when the symptoms are obvious, there may well be a reluctance to label someone with dementia because of the negative attitudes and stigma sometimes associated with the disease within families and communities. There may well also be an erroneous attitude that as nothing can be done for the patient in terms of a cure, it may be best not to create false expectations on behalf of patients or future demands on existing community care resources, which are already scarce. The new Strategy will have to confront the diagnosis issue from both the demand and supply side. In relation to the former, the public need much more information on the disease and its implications, thus creating higher expectations in regard to care pathways, including preventative strategies. In relation to the supply-side, further investment in memory clinics would widen and deepen diagnostic services. But equally important are targeted education and training programmes for health professionals, designed to equip them with the necessary skills to diagnose dementia, or at least to know enough to be able to refer people to facilities that could provide more comprehensive diagnostic information.

There are an estimated 50,000 carers in Ireland looking after someone with at least one of six specified symptoms of dementia: for example 25,000 carers are looking after someone with marked forgetfulness on a regular or occasional basis, while 15,000 people are looking after someone with confusion to the point of interfering with everyday life (O'Shea, 2000). The overall median daily provision of care provided by these carers to people with dementia is 10 hours, with some people caring for much longer hours per day. Under such strain, it is no wonder that caring becomes a burden for some people with serious consequences for physical and mental health. In reviewing the research evidence for this report, a substantive body of published literature was found, demonstrating that caring for a person with dementia compared with other caring roles, places much greater demands and strain on family members.



There is some evidence that family carers for people with dementia in Ireland would like to reduce caring hours, but none to suggest that carers would like to stop caring. Carers want to care, but would like more relief and more support from the ongoing burden of care. They also want to be more involved in the process of caring, including making decisions about the most useful services needed to help them in their caregiving roles. They are the experts and have an enormous amount to contribute as they are familiar with the past history and biography of the person they care for and many have become very resourceful in developing their own strategies for coping with the excessive demands of the dementia care role. Unfortunately, at the moment, they are either left to their own devices in respect of caring, or are ignored when it comes to joint decision-making between the state and the person with dementia. A key element of any new Strategy will have to be more formal partnerships between family carers and the statutory system of care. This will require the development of new administrative structures to link the informal with the formal as part of the development of co-ordinated person-centred packages of care that reflect the needs of people with dementia and their carers.

The contribution of family care is in contrast to the relatively low provision of community care for people with dementia. The evidence from this study confirms once again that community support services for people with dementia and their carers are under-developed and fragmented in this country. Generally, people with dementia do not come into contact with the health and social services until a crisis occurs, involving the person with dementia, their carer, or both parties. One of the resounding weaknesses of Irish home care services compared with those developed and delivered in other countries (such as the UK, Norway, Sweden, Denmark, France and Australia) is that these services are not underpinned by legislation and are not provided on a statutory basis. In simple language, we are not doing enough for people with dementia living at home in the community. It seems to be administratively and politically easier to fund buildings and new health technologies than it is to support the development of personal services for older people with dementia. That must change if we want genuine transformation in the way we look after people with dementia in this country.

In the absence of the required level of community support, people with dementia will continue to be placed in long-term care prematurely. That is all the more likely if the funding system continues to be biased in favour of residential care through the NHSS. Policymakers have not yet grasped the fact that families react to price incentives and use economic calculus when making decisions about long-term care placement. Any decision to introduce charges for home care packages in the future will further weaken the pull of community care relative to residential care. New investment in community-based facilities and services will yield significant returns. For example, day care and respite facilities are highly valued by those that have access to them currently, but there are not enough of them, and even where they do exist not all of them provide dementia-specific care in appropriately designed buildings. The goal of the Norwegian Dementia Plan 2015 is that every municipality should offer a day care programme and these should be available to the majority of community-dwelling people with dementia. It is our view that since day care is such a universally acknowledged and important community care service for people with dementia, the Irish government needs to develop a similar goal regarding day care service development for the 26,000 people living in the community with a dementia in this country.

In the short-term, given scarcity of resources, choices will have to be made about the reallocation of some of the existing institutional resources to community care. This will be painful and so will have to happen gradually to protect residential care spending which continues to be necessary, but spending on one person with dementia in the community can reach €50,000 per annum before institutional funding thresholds are reached. Funding through the residential NHSS should not be released for any applicant unless it has been shown that a similar allocation could not be used to support home care alternatives for that person. Furthermore, given what could be achieved through interventionist case management, integrated delivery and innovative psychosocial programmes, all of which can be delivered at relatively low cost, the development of a world class community-based care is not an unrealistic goal. This is what we should be aiming for in the medium-term of three years. As part of this process, local communities should be mobilised to provide moral and practical support for people with dementia and their carers living at home.

Based on the literature review conducted for this report, our belief is that the best way to ensure that people get the services they need is to develop a system of case management for people with dementia and have available 'dementia champions' (be they Admiral nurses or dementia advisors as is the case in the UK or specialist dementia teams as is the case in Norway and Sweden) to assist and support people in their journey through the disease trajectory. In this country, very few people with dementia have been allocated a case manager or even a key worker to directly represent their interests as consumers and citizens. A case manager would facilitate needs assessment, oversee the development of a care plan, co-ordinate the delivery of services and monitor outcomes. She/he might also nurture local supply-side responses to need among people with dementia from private and voluntary providers, thereby expanding the range and variety of services in local areas. Actively engaging communities in the planning and delivery of services is key to keeping older people with dementia out of long-stay care.

People with dementia can sometimes end up in A&E departments in acute general hospitals, or as in-patients in these hospitals. At the moment, the level of information on people with dementia in acute general hospital settings is poor in Ireland. While a small number of people are admitted to hospital with dementia as a primary diagnosis, mostly dementia within acute care is a secondary diagnosis, if identified in patients at all. Moreover, evidence from other countries suggests that some people would not have to be admitted to hospital at all for their particular primary illness were it not for the accompanying dementia; upon admission people with dementia tend to have longer length of stays than those without dementia for comparable illnesses. In recognition of the prevalence of dementia in general hospitals and in an effort to improve hospital dementia services, many countries, including England, Scotland, Northern Ireland, Norway and Australia, have prioritised improvements in care for people with dementia in this setting. The importance of improving the assessment and diagnosis of patients admitted to hospital who might have dementia (particularly when emergency admissions occur through A&E) is explicitly recognised in the Scottish National Dementia Strategy, as a gateway to better care and support, including appropriate long-term placement. The focus is on training general hospital staff to recognise the symptoms of dementia and to provide dementia-friendly care in hospital settings, right up to end-of-life if necessary.

The review of the literature undertaken for this report, including an assessment of best practice in other countries, identified a number of key issues that would help to improve the care of people with dementia in acute care settings in Ireland. In the first instance, improving primary care and augmenting community-based supports can delay or prevent hospital admission for people with dementia. Early detection and assessment of dementia (and delirium) while in hospital can also transform care pathways and care relationships for people with dementia, even after discharge. For this to happen, diagnostic expertise and facilities must be available in acute settings, supported by much greater dementia awareness and training among all hospital staff, in particular nursing staff. More person-centred communication strategies that directly involve family carers have also been shown to improve care for people with dementia in hospital settings; as does the reduction of internal and external stressors. Early discharge planning that is focused on returning the person with dementia to their own home is essential, requiring a multidisciplinary approach to care that is linked directly to the primary care system through dedicated liaison personnel and structures. A major part of any new Strategy in Ireland must be the transformation of care within general hospitals for patients with either a primary or secondary diagnosis of dementia using some, or all, of these approaches.

The needs of people with dementia in residential care are also important, given how many people with dementia live in this setting in Ireland. Unfortunately, hard information on the numbers of people with dementia in long-stay settings is largely absent, including data on the number and type of dementia specific accommodation. The definitions and classification of different types of nursing homes used in the Long-Stay Activity Statistics Report and the National Register on Public and Voluntary beds are anachronistic and are not fit for purpose; they need to be revised to reflect the considerable changes in residential care provision in Ireland in recent years. Given its statutory responsibility for health information, HIQA should provide regular summary statistics on people with dementia, including severity, in all registered long-stay facilities, as well as establishing a register of specialised dementia nursing homes and SCUs for people with dementia within nursing homes. There is also a need for a new and integrated dementia skills

and knowledge programme to guide formal training and education of staff working with people with dementia in residential care settings. This should be provided on a uniform and national basis and linked to ongoing and existing education and training structures.

International evidence points to the wisdom of providing care for people with dementia in long-stay settings in small-scale, homely and specialised care settings. Developing the ‘Teaghlach’ or ‘household’ model of care in combination with assisted living communities such as those provided by the FOLD Housing Association, should be a priority in the new Strategy. The care process within long-stay facilities is also important in allowing residents to live well with dementia. Psychosocial approaches are needed to complement medical and neurological models of service delivery. There should be more emphasis on developing meaningful communication with residents, using all of the senses, through reminiscence, music and various therapeutic and time-intensive activities. Innovation in, and evaluation of, psychosocial interventions for older people with dementia in long-stay care should be encouraged and facilitated through incentive schemes and innovation awards schemes at local level. Success should be judged on making people happy during the intervention and trying to improve long-term health outcomes. In particular, given the importance of connectivity for people with dementia in long-stay settings, new ways of reaching into and out of long-stay settings should be encouraged. Carer groups and voluntary organisations should be supported in developing connectivity programmes that link communities directly to residential care facilities. Appointing local champions for people with dementia would assist in maintaining the visibility of older people with dementia, whether living at home or in residential care facilities.

Finally, it is important to restate that this report is not a Strategy for dementia. Its purpose is to inform the development of a new Strategy through the provision of timely secondary research in a number of selected areas. There are, therefore, by definition, important areas not covered in this report. Any omissions can be addressed in the next phase of developing the Strategy when, we understand, there will be direct consultation with all stakeholders. Anyone looking for a template for the proposed new Strategy should consult the original Action Plan for Dementia (O’Shea and O’Reilly, 1999) which has stood the test of time in relation to philosophy, coverage and content. Our brief was to generate more contemporary data to support the proposed new Strategy and provide insight into the lessons learned from how other countries are dealing with dementia. Despite considerable limitations in respect of data on dementia in Ireland, we have managed to provide guidelines as to the future direction of public policy for dementia in Ireland covering:

- greater emphasis on prevention, particularly in relation to heart disease and stroke
- increased public awareness about dementia
- increase in early diagnosis through improving access to memory clinics and enhanced training and education for primary care workers, especially for general practitioners and nurses
- development of a case management model of integrated care
- expansion of dedicated community-based services, for example, day care services, for people with dementia and their carers
- development of new and expanded psychosocial approaches to complement existing medical and neurological models of service delivery in the community and in residential care units
- development of small-scale, appropriately designed, residential care units
- development of appropriate services for people with early-onset dementia, including people
- enhanced information systems on the number of people with dementia, severity of the disease, placement patterns and quality of life.

132 We are aware that the development of the new Strategy for dementia will take place under the most testing of financial circumstances. While it was not part of our remit to comment on the funding difficulties caused by ongoing austerity and retrenchment in the public budget, it must be acknowledged that dementia is competing for ever scarcer public resources. The allocation of resources to dementia is ultimately a political decision that can be influenced by stakeholders and public opinion. Even within such binding budget constraints, however, much can be achieved in the coming years through raising awareness, prioritising community care, co-ordination and integration of service provision, education and training, innovation, better ways of working and shared best practice. For the person with dementia the goal must be to provide them with an individualised pathway of care from prevention, through early diagnosis to end-of-life. At the macro level, the goal should be to make dementia a public health priority, thereby replacing a currently undiagnosed, invisible and marginalised dementia population with a diagnosed, visible and protected community.

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## List of abbreviations

<b>A&amp;E</b>	Accidence and Emergency
<b>AD</b>	Alzheimer's disease
<b>ADAMS</b>	Aging, Demographics and Memory Study (US)
<b>ADI</b>	Alzheimer Disease International
<b>ADL</b>	Activities of Daily Living
<b>AGECAT</b>	Automated Geriatric Examination for Computer Assisted Taxonomy
<b>AHP</b>	Allied Health Professional
<b>AIGNA</b>	All Ireland Gerontological Nurses Association
<b>AIHW</b>	Australian Institute of Health and Welfare
<b>ANP</b>	Advance Nurse Practitioner
<b>AP</b>	The Atlantic Philanthropies
<b>AR-DRG</b>	Australian Refined Diagnostic Related Group
<b>ASI</b>	The Alzheimer Society of Ireland
<b>BILD</b>	British Institute of Learning Disabilities
<b>CARE</b>	Creating Avenues for Relative Empowerment
<b>CNS</b>	Clinical Nurse Specialist
<b>CSHA</b>	Canadian Study on Health and Ageing
<b>CSO</b>	Central Statistics Office
<b>DHSSPS</b>	Department of Health, Social Services and Public Safety
<b>DkIT</b>	Dundalk Institute of Technology
<b>DRAH</b>	Dementia Rehabilitation at Home
<b>DCRC</b>	Dementia Collaboration Research Centre
<b>DRGs</b>	Diagnostic Related Groups
<b>DSDC</b>	Dementia Services Development Centre
<b>DSIDC</b>	Dementia Services Information and Development Centre
<b>ECAD</b>	Enhancing Care in Alzheimer's Disease
<b>ECU</b>	Extended Care Unit
<b>EHES</b>	European Health Examination Survey
<b>ESRI</b>	Economic and Social Research Institute
<b>EU</b>	European Union
<b>EuroCoDe</b>	European Collaboration on Dementia
<b>EURODEM</b>	The European Community Concerted Action on the Epidemiology and Prevention of Dementia Group
<b>GP</b>	General Practitioner
<b>HCP</b>	Home Care Package
<b>HELP</b>	Hospital Elder Life Program
<b>HIPE</b>	Hospital In-Patient Enquiry
<b>HRB</b>	Health Research Board
<b>HSE</b>	Health Service Executive

<b>ICGP</b>	Irish College of General Practitioners
<b>ICSG</b>	Irish Centre for Social Gerontology
<b>ID</b>	Intellectual Disability
<b>IHF</b>	Irish Hospice Foundation
<b>LHO</b>	Local Health Office
<b>LID</b>	Living with Dementia Programme
<b>MIMS</b>	Monthly Index of Medical Specialities
<b>MMSE</b>	Mini-Mental State Examination
<b>NDEP</b>	National Dementia Education Programme
<b>NESF</b>	National Economic and Social Forum
<b>NHI</b>	Nursing Homes Ireland
<b>NHS</b>	National Health Service
<b>NHSS</b>	Nursing Home Support Scheme
<b>NICE</b>	National Institute of Health and Clinical Excellence
<b>NIDD</b>	National Intellectual Disability Database
<b>NPIRS</b>	National Psychiatric In-Patient Reporting System
<b>NUIG</b>	National University of Ireland, Galway
<b>PLST</b>	Progressively Lowered Stress Threshold
<b>POCD</b>	Post Operative Cognitive Decline
<b>RCT</b>	Randomised Control Trial
<b>RGN</b>	Registered General Nurse
<b>SCIE</b>	Social Care Institute of Excellence
<b>SCU</b>	Specialist Care Unit
<b>TCD</b>	Trinity College Dublin
<b>TILDA</b>	The Irish Longitudinal Study on Ageing
<b>UK</b>	United Kingdom
<b>UN</b>	United Nations
<b>US</b>	United States
<b>VH</b>	Voluntary Hospital
<b>VWH</b>	Voluntary Welfare Home
<b>WH</b>	Welfare Home

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Title of Information Source	Data creator/ holder	Comment
National Censuses		
Census of Population, 2006	Central Statistics Office	<p>The Census of Population 2006 was used to arrive at:</p> <ul style="list-style-type: none"> <li>age and gender specific estimates of the number of people with dementia in Ireland;</li> <li>estimates of the number of people with dementia at regional and LHO level;</li> <li>an estimate of the prevalence of dementia in the community.</li> </ul>
Long Stay Activity Statistics, 2008	Information Unit, Department of Health	<p>A review of the Long Stay Activity Statistics revealed that the official figures significantly underestimate the number of people with dementia in long-stay residential settings.</p> <p>These statistics do not accurately reflect the level of dementia-related deaths that occur in nursing homes, nor do they recognise the care to people with dementia in 'nursing home beds' that integrates a palliative care approach, but are not categorised in the statistics on palliative care beds.</p> <p>The Long Stay Activity Statistics need to be revised to reflect the considerable changes in residential care provision in Ireland in recent years.</p>
Population projections		
Population and Labour Force Projections, 2011-2041	Central Statistics Office	<p>The CSO population projections were used to arrive at estimates of the population of people with dementia in Ireland for the years 2011-2041. These projections are important as indications of general trends but there are limitations attached and as such they should not be treated as precise figures.</p>

Title of Information Source	Data creator/ holder	Comment
Regional Population Projections, 2011-2026	Central Statistics Office	The regional projections published by the CSO are disaggregated to regional level but as this data is not age and gender-specific, it is not suitable for estimating regional projections of dementia (CSO 2008b).
National sources of health and social care information		
Hospital In-Patient Enquiry (HIPE)	Health Research and Information Division in the ESRI, in conjunction with the Department of Health and the Health Service Executive.	<p>The Hospital In-Patient Enquiry (HIPE) collects data on principal and additional diagnoses (including Dementia and other chronic disturbances of cerebral function) of hospital in-patients.</p> <p>HIPE is not a suitable source for estimating prevalence of dementia in acute hospital settings.</p>
National Psychiatric In-Patient Reporting System (NPIRS)	Mental Health Research Unit at the Health Research Board	Information on people with dementia in long-stay psychiatric hospitals and units, including average length of stay, can be obtained from the NPIRS.
National Intellectual Disability Database (NIDD)	Disability Databases Unit in The Health Research Board (HRB) in conjunction with the Department of Health.	The information provided by NIDD includes data on disability, levels of severity and age. The NIDD does not generate information on disability type and, therefore, provides no information on people with Down Syndrome.
HIQA Register of long-stay facilities	HIQA	<p>HIQA has statutory responsibility for health information, i.e. 'advising on the collection and sharing of information across the services, evaluating information and publishing information about the delivery and performance of Ireland's health and social care services'.</p> <p>HIQA does not provide regular summary statistics on the number and type of registered long-stay facilities.</p>

Title of Information Source	Data creator/ holder	Comment
		<p>HIQA does not collect information on the number of people with a known or suspected dementia in all registered long-stay facilities.</p> <p>HIQA does not have a register of specialised dementia nursing homes and Specialist Care Units for people with dementia within nursing homes to which the supplementary criteria for dementia-specific residential care settings for older people apply.</p>
Dementia Register		<p>There are registers in Ireland for some health conditions and illnesses including cancer, motor neurone disease and haemophilia, but a Dementia Register has not yet been developed.</p>
National Surveys		
The Irish Longitudinal Study on Ageing (TILDA)		<p>TILDA provides important information on cognitive function in older adults in Ireland, based on objective measures of cognitive function and self-rated memory. It also provides salient information on utilisation of health and social care services and on physical and behavioural health. TILDA does not currently include in its sampling frame people who are already diagnosed with dementia.</p>
Intellectual Disability Supplement to TILDA		<p>The IDS-TILDA collects information on Intellectual Disability and Dementia.</p>
National Disability Survey 2006	Central Statistics Office	<p>The National Disability Survey 2006 is useful for estimating the number of people with Down syndrome in Ireland.</p>

Title of Information Source	Data creator/ holder	Comment
Secondary data sources		
Old Age Psychiatry Database (HealthStat)	Health Service Executive	<p>The HSE maintains a database on Old Age Psychiatry services. However, no information or records are kept on utilisation of these services by people with dementia.</p>
Database on Home Care Services (HealthStat)	Health Service Executive	<p>The actual level of home care provision to people with dementia in Ireland is unclear, as the latter are not differentiated in the HSE database on home care services. In addition, there is no mandatory requirement that service providers collect detailed data on the delivery of home care services they administer to people with a known or suspected dementia. Accordingly, accurate estimates of the percentage of people with dementia using home care services are not available.</p> <p>Data on home care services needs to be made more accessible to researchers.</p>
Day Care Survey Database (HealthStat)	Health Service Executive	<p>The Day Care Survey does not provide reliable data on numbers of people with dementia using all day care services in Ireland.</p> <p>The Day Care Survey provides data on the number of day care centres and places that are specifically designated for people with dementia.</p> <p>The Day Care Survey was first carried out in 2009 and has not as yet been repeated.</p>

Title of Information Source	Data creator/ holder	Comment
National Register of Public and Voluntary Units and Beds (HealthStat)	Health Service Executive	<p>The National Register is one of two systems currently in place for collecting data on long-stay units and beds in Ireland. The National Register, which is updated on a monthly basis, collects data on long-stay beds in public and some voluntary settings, including on beds in Specialist Care Units for people with dementia. However, it does not collect data on units and beds in private and most voluntary long-stay care settings. It is possible from the National Register to generate data on units and beds disaggregated by HSE region and LHO areas.</p> <p>The National Register needs to be revised to reflect the considerable changes in residential care provision in Ireland in recent years.</p>
Elderly Register	Health Service Executive	<p>The HSE is currently in the process of introducing ‘elderly registers’ into each LHO which will include accurate diagnostic information on all clients.</p>
Statistical Information on Social Welfare Services	Department of Social Protection	<p>The Department of Social Protection collects data and provides statistical information on the number of recipients (disaggregated by gender and age group) of Carer’s Allowance, Carer’s Benefit and the Respite Care Grant as well as expenditure on these schemes.</p> <p>The Department of Social Protection does not collect data on the number of recipients of the above schemes who are caring for people with dementia.</p>

Title of Information Source	Data creator/ holder	Comment
Other Data Sources		
NHI Annual Survey of Private and Voluntary Nursing Homes	Nursing Homes Ireland	<p>The NHI survey of private and voluntary long stay beds collects data on long-stay residential care in Ireland.</p> <p>Whilst providing very useful information on private and voluntary nursing homes, its method of collecting and presenting data differs remarkably from the National Register. The NHI Annual Survey continues to use the 10 former Health Board areas as the basis for disaggregating data to regional level, whilst the National Register use HSE LHO areas.</p>
Alzheimer Society of Ireland Database of Service Utilisation	Alzheimer Society of Ireland	<p>Provides monthly information on the utilisation of ASI dementia-specific home care (including in-home respite care), day care and residential respite services by people with dementia disaggregated by geographical location.</p>



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<b>Acute care</b>	active short-term treatment for an acute illness, injury or medical condition.
<b>Best practice</b>	is a method or technique that has consistently shown results superior to those achieved with other means.
<b>Biography</b>	refers to an account of a person's life given by another. In dementia care the term biography is often used synonymously with life history.
<b>Challenging behaviours</b>	sometimes known as "behavioural and psychological symptoms" of dementia. A person with dementia may exhibit one or more of these challenging behaviours during the course of the illness. Challenging behaviours include agitation, aggression, wandering, sleep disturbance, inappropriate eating, inappropriate sexual behaviour, delusions, hallucinations and paranoia.
<b>Community care</b>	health, personal and social care services delivered in the community, including for example public health nursing services, home help services, home care packages, day care and respite care services.
<b>Cognitive impairment</b>	a cognitive decline greater than that expected for a person's age and education level.
<b>Early-onset dementia</b>	people who get dementia and are aged less than 65 years.
<b>Dementia</b>	a global or umbrella term used to describe a group of diseases that have common symptoms but different causes. Symptoms include impaired memory, language, ability to communicate, mood and personality. By far the most common type of dementia is Alzheimer's disease.
<b>End of life care</b>	the care that a person with a terminal illness gets at the final stage of life.
<b>Epidemiology</b>	the study of the distribution and determinants of health-related states or events including disease and the application of this study to the control of diseases and other health problems.
<b>Hospital In-Patient Enquiry</b>	a computer-based system designed to collect demographic, clinical and administrative data on discharges and deaths from all acute public hospitals nationally. The system is jointly managed by the ESRI and the HSE.
<b>Incidence of dementia</b>	refers to the number of new cases of dementia in the population over a given period of time. Incidence rates are usually represented as the number of new cases per 1,000 people per year.
<b>Life story</b>	the story of a person's life which may vary pending on who is telling that story and for what reason the story is being told.

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<b>Long-stay residential care</b>	public private and voluntary services providing care to people usually on a permanent basis and outside of their own home. Long-stay residential care in Ireland tends to be synonymous with nursing home care
<b>Memory clinics</b>	clinics primarily aimed at identifying, investigating, diagnosing and treating memory problems/memory disorders, including dementia. In the context of dementia, the distinguishing feature of Memory Clinics from other dementia care services is their focus on the individual needs of the person with dementia.
<b>Multi-disciplinary teams</b>	care teams that consists of a number of health service professionals, including medical doctors, nurses, occupational therapists, social workers, physiotherapists and speech and language therapists.
<b>Opportunity cost</b>	the cost of any activity measured in terms of the value of the best alternative that is not chosen (that is foregone). In the case of family caregivers who have had to give up work to care, the opportunity cost of care is the value of income foregone.
<b>Population projections</b>	estimates of future populations; for the purpose of this report, projections have been arrived at using certain combinations of fertility and migration assumptions.
<b>Reminiscence</b>	attempting to trigger memories from the past and use them for communication in the present. In dementia care, aids are often used including photographs, music, materials, and any relevant old objects.
<b>Prevalence of dementia</b>	refers to the number of cases of dementia present in a given population at a certain time.
<b>Resident</b>	a person living in a facility and being provided with services by a residential care staff.
<b>Primary care</b>	refers to the first point of contact that people have with health and personal social services. In Ireland, this contact is usually with GPs. The services and resources available within the primary care setting have the potential to prevent the development of conditions which might later require hospitalisation.
<b>Respite care</b>	a service designed to give family caregivers a break or rest from caring. Respite care can be “in-home”, meaning that the service provider comes into the person’s home and provides substitute care, or it can be provided outside the home at a “day centre” or it can be provided in a nursing home for a more prolonged period. The latter is commonly referred to as residential respite.
<b>Secondary care</b>	refers to specialist services, which may be either community or hospital-based. Secondary care services are generally used to address complex and more specialist needs which cannot solely be met through primary care services. In the context of older people’s services, Geriatric Medicine and Old Age Psychiatry are examples of Secondary Care Services.
<b>Stigma</b>	is the disapproval or labelling of a person, on the grounds of characteristics that distinguish him/her from other members of society. It is often argued that older people with dementia must overcome a double stigma that is due to both their age and the dementia.











