



FUTURE DEMENTIA CARE IN IRELAND

Sharing the Evidence to Mobilise Action

Suzanne Cahill, Eamon O'Shea and Maria Pierce

Copies of this Guide and the related report – Creating Excellence in Dementia Care: A Research Review for Ireland's National Dementia Strategy - are available to download from the Living with Dementia website (livingwithdementia.tcd.ie) and the Irish Centre for Social Gerontology website (www.icsg.ie)

To order a printed copy of this Guide and the related report, please email: forsythc@tcd.ie

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Foreword

Since the turn of the millennium, dementia has not simply stepped onto the national stage, it has, metaphorically speaking, put on its running shoes and sprinted into the very centre of the policy, service and research arena taking every opportunity along the route for its messages to seep into the public consciousness. The pace of this change has been breathtaking and has been spurred on by a number of factors, such as the availability of more sophisticated measures to predict the numbers of people living with dementia (both now and into the future), public concern and a more dementia-aware and friendly policy architecture. This has culminated in local service providers being required to produce individualised and tailored services and action plans for people with dementia and their care partners and, more importantly, to be accountable for them. This is not simply a local or national event, but a world-wide movement with a momentum all of its own.

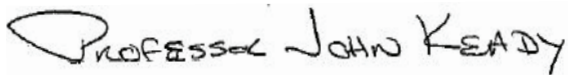
Having been familiar with the full report 'Creating Excellence in Dementia Care: A Research Review for Ireland's National Dementia Strategy' and now this condensed Guide drawn from the same source, my first thoughts are to congratulate each of the authors, Associate Professor Suzanne Cahill, Professor Eamon O'Shea and Dr Maria Pierce.

Distilling key research-based evidence, information and messages into an accessible format is not an easy task, and the fact that this Guide reads so seamlessly, so effortlessly, yet with such authority, is to each author's enormous credit. As this Guide makes clear, in Ireland there are currently around 42,000 people living with dementia with around 3,500 of this total aged under 65 years. Why is this important? Well, by and large, human beings live within a set of social, relational and community-based networks. In other words, we have family, friends and a life 'outside the front door' where we act out our everyday lives. From shopping at the supermarket to exchanging pleasantries with our neighbours, all these social actions, networks, spaces and relationships are important and play a crucial role in sustaining and maintaining our quality of life, be we living with dementia or not. It is, therefore, incumbent on us all to ensure that people with dementia are not excluded from being full and active citizens of the community of which they are a part and have opportunities for continued self-growth, wellbeing and everyday life.

Most developed countries now have - or are in the process of developing - a National Dementia Strategy and 'dementia' is on the lips, and action plans, of politicians. Ireland, of course, is no

exception and will soon have its own National Dementia Strategy. The public narrative has now turned, where once dementia was present but silent, now it is present but heard. The policy and service push for early diagnosis means that more and more people with dementia will have an opportunity to not only be actively engaged in the debate about their own lives and futures, but to actually shape it. Inclusivity is all. This is a crucial step forward and whilst the mechanisms for supporting the voice and participation of people with dementia continue to evolve, it is happening. In time, people with dementia will spearhead this new vision. To return to the metaphor at the start of this Foreword, it will be here where the baton will be passed and the race run in collaboration, not in competition. For people with dementia and their care partners that is a finishing line worth striving for; this Guide fires the starting pistol.

John Keady PhD RMN RNT
Professor of Older People's Mental Health Nursing

A handwritten signature in black ink that reads "Professor John Keady". The signature is written in a cursive, slightly stylized font.

The University of Manchester/Greater Manchester
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Introduction

A major challenge facing societies across the world today is population ageing. The fact that people are living longer and the notable improvements in the overall quality of life and well-being of older people today needs to be celebrated. However, population ageing will inevitably result in an increase in disability and a very significant increase in the incidence of age-related health problems especially Alzheimer's disease and the related dementias. Increasing age is by far the single strongest risk factor for dementia and a person at the age of 90 runs a 50% higher risk of developing a dementia compared with someone in their

60s. In fact, over the age of 65 the prevalence of dementia nearly doubles every five years.

Worldwide, an estimated 35 million people have dementia, and in Europe alone, about 7 million people are living with dementia. These figures are expected to double every 20 years. Currently, there is no cure for dementia and people can live a long time after diagnosis. Dementia is a hugely costly public health issue, more costly than coronary heart disease, cancer and stroke combined. A recent *World Alzheimer Report* estimated that the global cost of dementia was in the region of US\$604 billion. Yet, for some reason, dementia remains a neglected illness. It is often hidden in our society

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and undetected by doctors or specialists. Within Ireland dementia fails to attract the budgetary and political attention of other major illnesses.

Like other countries, Ireland is soon to witness a very significant growth in its ageing population and, as a result of this, a parallel increase in numbers of people likely to have dementia. This burgeoning in numbers of people with dementia will result in very significant economic, social and psychological costs for Irish society. Dementia is different from other illnesses - for every one person diagnosed three other family members will be significantly affected. Because of the rising tide of dementia, careful planning is needed now to ensure that action is taken to develop and expand services for all those affected by this illness with a view to improving quality of life. Ireland now has a golden opportunity to become a world leader in dementia care and to learn from the successes and failures of other countries who have already developed their own National Dementia Plans/Strategies. Given that the Irish Government has recently made a commitment to develop a National Dementia Strategy and to implement this Strategy over a five-year period, we must seize this welcome opportunity to carefully plan effective person-centred dementia care services. The time for action is now, not tomorrow or next year.

This practical Guide sets out the key findings emerging from a recent research review, conducted to inform the development of Ireland's future National Dementia Strategy. The review, which culminated in a report titled *Creating Excellence in Dementia Care: A Research Review for Ireland's National Dementia Strategy*, was written by Associate Professor Suzanne Cahill (TCD), Professor Eamon O'Shea (NUIG) and Dr. Maria Pierce (TCD). During the course of the review, a multi-disciplinary Dementia Advisory Committee met on a regular basis to guide and inform the work. The research work was funded by The Atlantic Philanthropies and supported by the Department of Health. The potential key elements of this new Strategy and the next steps for public policy on dementia are discussed in more detail in this practical Guide.

"Dementia is important because of the profound effects that it can have on the people who develop it and on those close to them; because it is common; and because of the high demands it places on health and social care resources"

(Nuffield Council on Bioethics, 2009)



Photo: Ken Finegan

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What is Dementia?

Dementia is a general clinical term used to describe a group of disorders that have common symptoms but different causes. These symptoms include impaired memory, impaired judgement, impaired reasoning, impaired problem-solving skills and impairments in language, communication and social skills. In the early stages, the symptoms and changes in behaviour caused by dementia are slight and may go unnoticed; the person may look healthy and manage quite independently, aware that something is not quite right but able to conceal the difficulties experienced. As dementia progresses these difficulties usually become more pronounced and the person will need help with both simple and complex tasks.

There are several diseases and conditions that cause dementia. Alzheimer's disease is by far the most common form of dementia. Its symptoms, in the early stages, can be subtle and insidious, and the illness is sometimes said to "creep up" on people, with the person often experiencing good days and bad. Vascular Dementia (caused by a stroke or a series of strokes sometimes so small that they remain unnoticed) is the second most common type of dementia. The symptoms of Vascular Dementia tend to occur more abruptly and it is said that this type of dementia follows a

step-wise progression with the symptoms often corresponding to the timing of the stroke or damage caused to the brain. Less common forms of dementia are Dementia with Lewy bodies and Fronto-temporal dementia (including Pick's Disease).

"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)

There are many other rarer diseases that may lead to dementia, including Progressive Supranuclear Palsy, Korsakoff's syndrome, HIV/AIDS, and Creutzfeldt-Jakob disease (CJD). These diseases may also result in mood and personality changes or the person engaging in unusual or disinhibited behaviour. Some people with Multiple Sclerosis, Motor Neurone Disease, Parkinson's disease and Huntington's disease may also develop dementia as a result of these illnesses. Mild memory loss and a minor slowing of thought processes are a typical part of ageing but it is important to realise that dementia is a disease process and not a normal part of ageing. Dementia has no single cause and generally no cure. Most dementias are progressive conditions (that is they develop and worsen over time) and will eventually adversely impact on many areas of that person's life.

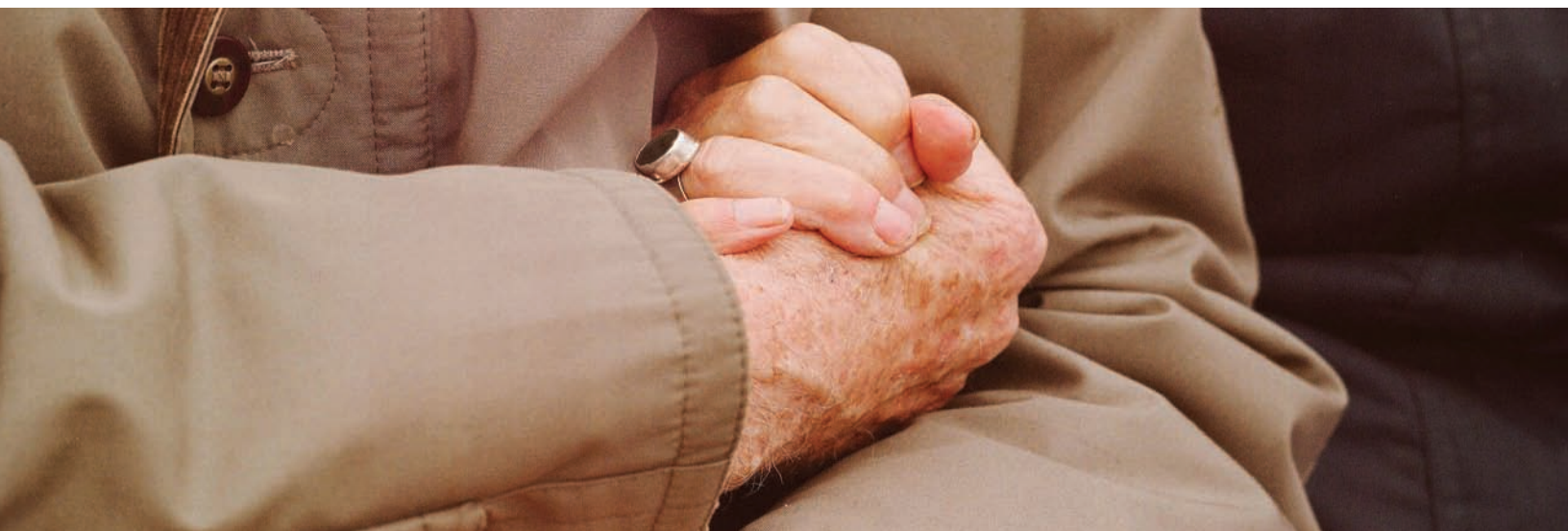


Photo: Ken Finegan

Many known and unknown modifiable (environmental) and non-modifiable (age, gender, genetics) factors can influence the onset of dementia. Despite what we know about the range of factors that contribute to dementia (such as head trauma, high blood pressure, high cholesterol, diabetes and stroke), increasing age remains by far the single strongest risk factor. Over the age of 65, the prevalence of dementia nearly doubles every five years. A very rare form of dementia called “early onset Alzheimer’s disease” results in the appearance of disease symptoms before the age of 65 (see page 12). This type of dementia is often related to specific gene changes. It affects only 5% of all those who have Alzheimer’s disease. People with Down syndrome are particularly susceptible to dementia.

We cannot control our age, gender or genetics, but there are a number of lifestyle approaches and precautionary measures we can adopt to help reduce the risk of our developing a dementia in later life. Indeed, some countries around the world like Australia and Canada have been very successful in developing risk reduction programmes and educating the public at large about ways in which they can “mind their minds”, to either delay or avoid developing dementia. Simple approaches that may help to delay or avoid getting a dementia include enjoying a healthy balanced diet, consuming alcohol in moderation, avoiding a severe blow to the head, engaging in new learning, keeping active, and reducing stress.

Dementia is a life changing condition and a

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diagnosis of dementia is often very distressing for the individual and for immediate family members. Dementia is not a one-person illness and it is said that for every one person diagnosed, three other family members are significantly affected. For the person, the illness can be experienced as stigmatising, particularly for those who have retained insight and who may be aware of their difficulties - trying to follow a normal conversation or recognise everyday objects such as the cooker or the toilet - to the point where others become exasperated and react with impatience, anger or ridicule. The person with dementia may feel isolated and may be regarded by others as hard to talk to, unpredictable and irrational in behaviour. The result may be that friends, neighbours or work colleagues may choose to distance themselves from that person who, as a result, may gradually become socially isolated. Guilt, apathy and social withdrawal are not uncommon in people with early onset dementia.

Nowadays, a lot more is known about dementia compared with even ten years ago. The development of new drugs for Alzheimer's disease, for example, has created hope for many. Although a few drugs may provide short-term relief and may temporarily improve memory and cognitive symptoms, sad to say, drugs which tackle the underlying disease causing the dementia have yet to be developed. Other mechanisms

for coping with dementia include using memory aids, having assistive technologies (devices designed to promote memory such as recording devices for reminders and other aids for more independent living) installed at home, and ensuring that as far as possible routine is maintained.

Each person's experience of dementia is unique and no two people with dementia will experience exactly the same symptoms. Some people may want to know more about their dementia whilst others will not. However, learning more about dementia may help the person deal with the impact that the diagnosis has on his or her life and may enable that person plan for his/her future.



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How many people have a dementia?

Dementia is a global issue of great concern to both developing and developed countries. There are about 35 million people around the world living with dementia, of whom approximately 7 million live in Western Europe. In Ireland approximately 41,470 people are likely to have dementia, although many have never been diagnosed.

There is also much regional variation across Ireland in relation to dementia prevalence - a term which refers to the number of cases of dementia present in a given population at a certain time. Roscommon, for example, has the highest prevalence of dementia. Dublin North has the lowest prevalence. These differences in prevalence rates are largely attributed to the differences in the age profile of people living within these different regions. Other counties in the West of Ireland such as Galway, Mayo and Leitrim have larger numbers of people with dementia because the average age of the population in these counties is higher than across the rest of Ireland.

Our estimates of dementia prevalence rates in Ireland (around 42,000 people) are not insignificant, but they are small, compared with other countries with larger ageing populations. For example,

in the US today, there are about 5.4 million people with dementia and there are as many as 750,000 in the UK who have a dementia.

However, we know based on recent research that the numbers in Ireland will increase very significantly in future years, given our ageing population. Our calculations show that by 2041 the numbers of people in Ireland with dementia will have tripled. In fact, a conservative estimate (based on calculations done for this review) suggests that by 2041 some 140,000 people will have dementia. Rather than causing alarm these estimates should enable us to plan services in the best possible way for the future. We can learn much from those overseas countries that have well developed policies and National Strategies/Plans in place to address the needs of those affected by dementia.

"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"

(Brodaty, 2008: 11)



How many younger people in Ireland have dementia?

As mentioned earlier, age is the strongest risk factor for dementia and the vast majority of people in Ireland who have dementia are aged over 65 years. However, there are about 3,583 Irish people with early onset dementia. These are an exceptionally vulnerable group of people about whom little is known. Very few of these young people with dementia use any community services; a fact not surprising given their age

profile and given they do not easily fit into service systems and structures established for older people with dementia. Approximately half of these people with early onset dementia are said to have what is known as “familial Alzheimer’s disease”, where a genetic predisposition leads to their disease. The other 50% share the same traits as people with ‘late onset’ Alzheimer’s disease. Little is understood about how and why the illness starts in these people at such a comparatively young age. Non-familial early onset Alzheimer’s disease can develop in people who

are in their 30s or 40s, but this is extremely rare.

The majority of people with early onset dementia (rare type of dementia) are in their 50s or early 60s and the challenges this type of dementia poses to the individual are multiple and complex. Given the difficulties older people often have trying to get a diagnosis, the younger person is likely to experience even more barriers and may feel extremely isolated and excluded. Work routines, family life and leisurely activities may be seriously affected as signs and symptoms of the illness become more apparent to friends and family members including siblings and young children. Job safety may be at risk and income security threatened. This group of people may also experience low self-esteem and may have difficulties as their personal and family relationships become adversely affected. The younger person with dementia may feel demeaned and frightened.

People with an Intellectual Disability can also develop dementia but those with Down syndrome are particularly at risk because of their unusual chromosome composition. The onset of the symptoms of Alzheimer's disease in this group of people generally occurs sometime between the mid-30s to the 60s. We know that in Ireland there are about 700 people with Down syndrome and dementia so combining these numbers with those who have early onset dementia means that

"For the younger individuals with dementia and their family members, the disease occurs 'off time', not in their older years, as most often expected, but in the prime of their lives"

(Harris and Keady, 2009)

there are about 4,283 people in Ireland with this unusual rare form of early onset dementia.

A lot more resources need to be invested in Ireland to help these younger cohorts of people cope with the symptoms of the illness and with the social and financial disadvantages encountered as a result of their getting this illness so early in life. Norway, a country with a population similar in size to Ireland, has 30 day centres built specifically to support younger people with dementia. In the UK, a myriad of services designed specifically for younger people with dementia are available across different regions. Unfortunately, there are very few dedicated services available for younger people with dementia in Ireland.



Photo: Ken Finegan

What are the costs of dementia?

Dementia is a very costly condition given its duration (people can live for a very long time after diagnosis), disease burden and the level of disability associated with the illness over time. In fact, the overall societal cost of dementia exceeds that of coronary heart disease, cancer and stroke combined. In the UK, dementia was estimated to have cost the Exchequer just over £17 billion in 2005/2006. Our recent research review has estimated that the overall economic cost of dementia in Ireland for 2010 was over €1.69 billion. These costs include the opportunity costs (income opportunities foregone) of family caregivers (€807 million), formal health and social services including the

cost of drugs (€88 million), hospitalisation (€21 million) and residential care (€731 million). In analysing the financial cost of dementia what is particularly striking is the fact that almost half (48%) of the overall costs of dementia in Ireland are borne by family and friends who provide the much needed care services required. A further 43% is accounted for by care in long-stay settings, while formal health and social care services contribute only 9% of the total costs of dementia. The average cost per person with dementia is estimated at €40,500 per annum. This is consistent with estimates from other countries.

The financial cost of dementia is only one aspect of the overall cost of this progressive illness. The non-economic costs of dementia care include

the social, emotional and psychological strain the illness confers on people with the condition and their carers. These costs are perhaps more difficult to identify than the economic costs since they are usually hidden and family members may be reluctant to talk about such costs or complain to others. We know, however, that dementia care is different from other forms of caregiving as it tends to extend around the clock and can involve both hard physical labour as well as serious psychosocial challenges.

We also know that most of the care given to people with dementia in the community is provided by adult children and spouse carers, many of whom are frail and elderly themselves and may not enjoy good physical health. Older spouse caregivers often become so engulfed in the caring role that their social networks and connections reduce to the point that they have very limited contact with the outside world. Many family caregivers may feel guilty about asking for help and often allow their own health and well-being to be adversely affected by the demands of the caring role.

For adult child caregivers, sources of strain arising from caring may be different. Daughter carers are often “women in the middle” who are sometimes caught in the trap of inter-generational caring, trying to provide care to a parent with

dementia, whilst simultaneously looking after young children. Some of these younger carers are also working in the paid labour market. Many feel guilty believing they have insufficient time for their children or spouse. They may also feel annoyed about the fact that brothers, sisters or other close family members have not been more supportive. The result is that they can become frustrated as no one person or aspect of their complex lives is getting their full attention.

Earlier research conducted in Ireland suggests that self-reported stress levels amongst Irish carers are high by international standards. Our research review has shown that family caregivers in Ireland do not receive the supports needed to enable them to easily sustain the care role. In the absence of regular breaks (respite), some studies

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

(Cahill, O’Shea and Pierce, 2012)

have shown that the decision to place a relative in long-term care is more related to carers’ own subjective feelings of stress rather than to objective indicators such as the severity of the dementia.



Who is responsible for diagnosing dementia?

Many people still believe that memory problems are a normal part of ageing and do not think they need to seek out medical help when they experience significant problems associated with their short-term memory. Others delay making an appointment with their GP because they are frightened about the prospect of being diagnosed with Alzheimer's disease or a related dementia and want to avoid hearing the truth about their condition. If you are worried about your memory and believe it is not as sharp as before, the first step towards seeking a diagnosis is arranging an appointment with your GP. Memory problems are not always necessarily caused by dementia. In fact, cognitive and memory problems may be caused by a variety of medical conditions, some of which are reversible and can be treated. Examples include depression, infections, abnormalities in the level of hormones and vitamin deficiencies.

It is not known how many people living with dementia in Ireland have actually received a diagnosis. In Scotland and England, GPs are compelled to keep registers documenting the numbers of patients known to have dementia attending their surgeries. Comparing these

"It is an important part of a GP's work to be familiar with the clinical symptoms of dementia and listen to the family carers who are likely to be the best positioned in providing information about the cognitive capacity of the individual"

(Dr Steve Jambleton, President Australian Medical Association)

figures against local prevalence rates makes it possible to calculate estimates of the numbers who have and have not been diagnosed. For example, in the UK, it is estimated that only about 40% of people with dementia have a diagnosis. However, in Ireland, to date, no similar dementia register requirement exists so we have no idea in Ireland who has received a diagnosis.

In Ireland, as in many other countries, a diagnosis of dementia is often not made at all or else it is made so late that the memory impairment, disability, behavioural and other symptoms can be quite serious and much pain and anguish has already been experienced. Expert opinion is that earlier and accurate diagnosis is important for the individual and for family members due to the benefits a diagnosis bestows. For example, if made earlier, a diagnosis may enable the person to take more



control of his/her own financial and legal affairs, and may help to reduce arguments and tensions at home. Acceptance of the situation may be easier for all, if a diagnosis makes others aware that the person's forgetfulness and changed behaviour is not deliberate - that it is caused by an organic problem and that no amount of nagging will change this behaviour. A differential diagnosis (knowing the dementia sub-type) may also help to determine the appropriate treatment as some drugs can have very adverse effects if offered to people with unusual dementias. An early diagnosis may also prevent a person making poorly informed financial decisions, which may

ultimately result in significant monetary losses. Making a diagnosis of dementia is not easy and Irish research has shown that many GPs, like their counterparts in other countries, are reluctant to get involved in the area because of lack of confidence, lack of training, stigma, difficulties differentiating normal ageing from the signs and symptoms of dementia and resource issues.

In other countries such as England, Scotland and Wales, financial incentives exist to motivate GPs to take a bigger interest in this area. In Scotland concern about the under-diagnosis of dementia by GPs has led their National Health

Service Boards to establish agreed targets for improvements in early diagnosis and for appropriate service responses for people with dementia.

In Norway responsibility for the diagnosis of dementia lies in primary health care except in unusual cases as, for example, when people have borderline scores on dementia assessment scales or where the presenting symptoms are atypical or experienced by those under the age of 65. In these cases, people are referred to Memory Clinics.

Based on our review, it seems that for Ireland a multi-pronged approach to assessment and diagnosis may be the preferred option: that assessment and diagnosis should be undertaken by GPs working alongside primary care teams, with input from specialist services including Geriatric Medicine, Old Age Psychiatry, Neurology and Memory Clinic staff. There is a need to integrate GPs and specialists, and for secondary services and specialists to support GPs in the ongoing management of people with dementia in the community.

Getting a diagnosis of dementia is said to be the first step in the journey through dementia in which everyone, as some Swedish experts argue, is entitled to a first class ticket. As will be shown on page 21, service supports for dementia in Ireland are fragmented and limited

but having no diagnosis may make people with a dementia ineligible for what are already very limited services. Common support needs of people with dementia and their families include information, services aimed at helping those recently diagnosed to come to terms with the diagnosis, and supports to maintain functioning and reduce disability. However, there is an absence of these types of support services around the time of and immediately after diagnosis in Ireland. There are some signs of an increasing awareness that more services and supports are needed in Ireland. An interesting innovation, for example, has been The Alzheimer Café, launched in 2011, where people with dementia and their family caregivers can meet in a relaxed atmosphere in the presence of health and social care professionals to discuss day-to-day living with dementia. The Genio Dementia Programme is also an exciting new project designed to develop and test new service models based on a community development type approach for people with dementia. This programme is jointly funded by the Health Service Executive and The Atlantic Philanthropies and is soon to be implemented. One of the key goals of the programme is to heighten community awareness about dementia and to encourage people to come forward to receive an early diagnosis. Four different communities across the country have now been chosen to participate in the programme.



Where do people with dementia live?

The research review has shown that there are 26,104 men and women in Ireland living at home with dementia and attempting to remain independent with the help of family carers. We know that there are about 50,000 family caregivers of people with dementia in Ireland. These caregivers are central to the community care system in Ireland, but very few of them

receive financial compensation from the state, by way of a Carer's Allowance or Carer's Benefit. Caregiving for a family member with a dementia is not easy work. It involves both labour and love; it is an activity and an identity; it is personal and political and sometimes the role is not taken on willingly or voluntarily but rather happens by default and builds up incrementally over time. By far the majority of families want to care but they want more recognition, support and relief from this hard work. Families also want to be more involved in the process of caring, including

making decisions about the services needed to help them in their caregiving roles. A key element of any new National Dementia Strategy will have to be more formal partnerships between family caregivers and the formal system of care.

One of the biggest weaknesses of community care services in Ireland is that services are not underpinned by legislation so people do not have a right to demand a particular service based on their circumstance. Community care services such as home care packages, day care and respite are fragmented, inequitable and under-developed. If we look at one particular service alone, day care, our research review has shown that in 2009 there were a total of 1,727 places available in dedicated dementia day centres for the 26,000 people in Ireland living with dementia. The research review also shows that in counties such as Roscommon, Mayo, Galway and Sligo - known to have a large proportion of people with dementia - there is a significant paucity of memory clinics, dedicated day care services and home care packages. Roscommon, the county with the highest proportion of people with dementia, has neither dementia-specific nor dementia-focused day care. In the absence of the required level of community care supports, families are placed under greater demands and strains trying to provide around the clock care and to prevent their relatives with dementia

being placed in long-term care prematurely.

Specific support services designed to respond to the unique circumstances of younger people with dementia in Ireland need to be considered in planning and developing community care services. 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. Current thinking suggests that people with intellectual disability who develop a dementia are best cared for by services providers who have specific intellectual disability expertise. However, staff working in this specialist field often lack dementia care knowledge and skills.

"There's a lot isn't there to be said to come home and to lock your door and it's your own place ... and do what you like" (Person with dementia)

(Bamford and Bruce, 2000)



What proportion of people in hospital have dementia?

Evidence from other countries suggests that many older people admitted to hospitals have dementia, but reliable and valid data about the prevalence of dementia in Irish hospitals remains poor. The research review suggests that up to 25% of all hospital patients may have dementia, yet since dementia is often hidden in the community it may continue to remain undetected following hospital admission. Even when older people are admitted to hospitals through Accident and Emergency and undergo careful assessment, dementia is often overlooked. This is not surprising given that the reasons why people with dementia are admitted to

hospital are more often related to other age-related medical complaints rather than the dementia or to their social circumstances such as a breakdown in caregiving arrangements.

The hospital experience can be hugely frightening and disturbing to a person with dementia who needs a stable and consistent environment that ideally reinforces self-identity and personhood. The hospital setting, complete with multiple and competing stimuli, including noise, ward rounds, poor signage, visitors coming and going, and regular staff changeovers, is far from ideal for a person with a severe cognitive impairment who is already prone to disorientation, fear and panic. General hospital staff do not always have the necessary skills and expertise required in

dementia care. For example, one Irish study showed that only 5% of general hospital nursing staff had received dementia training in recent years. Caring for patients with dementia in hospital who exhibit challenging behaviours such as aggression, paranoia, hallucinations or sleep disturbance can be particularly difficult for hospital staff.

Once admitted to hospital, people with dementia often have worse outcomes than older people without dementia. The evidence suggests that their length of stay in hospitals is usually longer and more costly and they are more likely to be discharged to a residential care setting. They are also known to have higher rates of other illnesses and higher mortality rates and often acquire new dependencies as a result of their being inactive for prolonged periods.

In other countries, including Scotland, the US and Australia, innovative approaches have been adopted towards the care and treatment of people with dementia in hospitals. These include the development of Dementia Champion programmes, which includes the appointment of specialist staff within the hospital with a dementia remit. These are qualified staff, who take ownership of patients with dementia in hospitals, and who help raise awareness about dementia and encourage more person-centred approaches to care. Other approaches used internationally include outreach and community-based specialist dementia services

which reduce the risk of hospital admission for people with dementia in the first instance.

There are many reasons why hospital staff should be aware if patients have dementia, not least the fact that people admitted to hospital with dementia are at an increased risk of developing a delirium. A dementia champion's programme in general hospitals would facilitate a more person-centred approach to care and would help to raise awareness of dementia care in such a challenging environment. There is a need to develop better hospital patient information systems yielding data that will more accurately reflect admissions, re-admissions, length of stay, and discharge of people with dementia from hospitals.

There needs to be a major review of the care of patients with dementia in general hospitals in Ireland. Staff need to be more aware of the likelihood that older patients being admitted to hospital will have a dementia. They need to be up-skilled in recognising the symptoms of dementia, in communicating this information to other staff members in other departments and in providing dementia-friendly care in hospital settings.



Photo: Mount Carmel Nursing Home, Clonakilty

adapt best to small-scale environments which are purpose-built, domestic (home-like) and have separate rooms for separate functions. In particular, large institutional multi-bed wards are totally inappropriate for people with a dementia.

Accessing long-stay facilities that are dementia-friendly in Ireland is not always easy. The public need to be better informed and educated about the location of these facilities, the admission and discharge criteria (some long-stay settings do not provide end-of-life care) and the services that are or are not on offer within. They also need better advice and information about how to decide when is an appropriate time to initiate residential care and how to communicate news of the transfer and relocation to their relative with dementia. In-depth information, advice and a culture of transparency is needed about the respective costs and benefits to the family of residential care, particularly in private nursing homes. Access to physiotherapy, chiropody and occupational therapy services, eligibility to medical treatments under statutory schemes, for example, the Medical Card and Drugs Payment Scheme, and any indirect costs need to be discussed up front with families placing their relatives in long-stay care. There is a legal requirement – under the Health Act 2007 (Care and Welfare of Residents in Designated Centres for Older People) Regulations, 2009 – for the long-stay care provider to agree a contract with each resident, to include details of services to be provided and fees to be charged.

How many people in residential long-stay settings have dementia?

The review estimates that there are currently about 14,000 people with dementia living in residential long-stay settings across Ireland, a figure which is considerably larger than the figure of 5,880 estimated using official government long-stay activity statistics. This means that about two-thirds of all people in long-stay care have a dementia. Our research suggests that most of these people are living in generic settings, sharing accommodation with other residents who do not have dementia. Whilst much debate exists about the advantages and disadvantages of integrating versus segregating people with dementia in long-stay care, experts in the field argue that people with dementia

Residents should not be charged additional fees over and above the cost agreed, except where the resident chooses to obtain additional services.

People with dementia are particularly sensitive to their built and psychosocial environment and, for some time now, environmental design has been regarded as critical to the care of people with dementia. In Ireland, there are few alternatives to the traditional nursing home model of care. Whilst some facilities have dementia-specific beds, these are the exception rather than the rule, and Specialist Care Units for people with dementia in Ireland do not always comply with international best practices norms. Developing the 'Tealghlach' or 'household' model of care in combination with assisted living communities should be a priority in the National Dementia Strategy.

People with dementia living in long-stay facilities need to be cared for by trained staff with excellent dementia skills and expertise in the care of older people. There is 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. The care process within long-stay facilities is also important in allowing residents to live well with dementia. There are a whole range of psychosocial approaches that can be used by trained staff to promote well-being and improve

quality of life for people with dementia in residential care settings, including meaningful communication with residents, reminiscence work involving all the senses, music and various other therapeutic activities. Approaches like these could be encouraged through incentive and innovation award schemes. Given the importance of connectivity for people with dementia, new ways of reaching into and out of long-stay settings should be also encouraged for carers groups and voluntary organisations.

Neither the Department of Health's Long Stay Activity Statistics nor the National Register on Public and Voluntary beds provides reliable data on people with dementia in residential long-stay care. Given its statutory responsibility for health information, the Health Information and Quality Authority (HIQA) should provide regular summary statistics on people with dementia in all registered long-stay settings as well as establishing a register of specialist dementia nursing homes and specialist care units for people with dementia within nursing homes.

"In many ways the principle for residential facilities – '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)



What are other countries doing to plan for dementia?

With the growing numbers of people worldwide affected by dementia, other countries around the world have developed National Dementia Plans or Strategies underpinned by evidence-based research. Their national plans have been developed to support investment in infrastructure, administrative systems and services for people with dementia and to ultimately help people live a better, more fulfilling life despite dementia. The various plans that are now in place are relatively consistent in their message regarding what needs to be done. Most of these Strategies emphasise personhood, primary prevention such as avoiding or delaying dementia, changing attitudes to the disease, diagnosis, improving quality of life and quality of care, training and

education for staff in dementia 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 also identified key priorities, which tend to both converge and diverge across countries. For example, Australia has included a strong focus is on primary prevention, on risk reduction and on delaying dementia. In Australia another focus is on the development of community care packages and on support and information for people with dementia and their families. 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, including raising public awareness of dementia, improving access to diagnosis and care pathways and building more Specialist Care Units to cater for the complex needs of people with serious challenging behaviours. The French National Plan has also emphasised the importance of increasing support for family carers. It has well-defined measures and outcomes to guide the evaluation of the progress of the Plan. Scotland emphasises key service delivery systems including improving services after diagnosis and improved care in general hospital settings. The

Scottish plan also emphasises the importance of access to quality care. The main success noted to date with the Scottish Strategy is the development of dementia care standards and a skills and knowledge framework to inform dementia training.

The English Strategy, *Living Well with Dementia*, involved over 3,000 people in initial consultations and set down four key priorities. These were early diagnosis, improved hospital care, improved quality of care in care homes and a reduction in the use of antipsychotic medication. The approach to consultation was particularly noteworthy with events being held in over 50 areas around the country and a carefully crafted consultation document developed which yielded about 600 responses. A key feature of the Strategy was the fact that an implementation plan was also published setting out how the Department of Health would support the delivery of the Strategy through its national and regional structure.

What each of these and 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 to live well with dementia. Most of the Strategies have been developed in consultation with professional stakeholders and community members, including those with dementia and their carers. In a number of countries including Australia and Scotland,

individuals with dementia or family carers have been included in steering or oversight committees. Adopting this approach helps to ensure that the evolving Strategies are relevant to the user groups and are, therefore, more likely to lead to real changes for people with dementia. Almost all of the strategies have been successful in generating additional resources for dementia, most noticeably in France, where there has been a significant increase in public investment in dementia care. The French Plan for the period 2008-2013 had a budget of €1.6 billion. The Australian Dementia Initiative had a budget of \$320 million. Scotland's National Dementia Strategy had a budget of €150 million for the period 2010-2013. Despite such successes in the form of sizeable budgets ring-fenced for service development, in most countries, dementia continues to lag behind other chronic diseases in terms of overall budget allocation, and in the share of resources devoted to research on the topic.

"A number of countries have recognized that without a coordinated plan to address dementia, individuals with dementia will not have access to the specialised services and supports they require. Some countries have already implemented a plan to address dementia"

(Alzheimer's Australia, 2011)



What is Ireland doing in its campaign on dementia?

As stated at the beginning of this document, a research review to inform and provide the evidence base for Ireland's forthcoming Dementia Strategy was commissioned in late 2010 and undertaken by a group of researchers from Trinity College Dublin and the National University of Ireland, Galway, in 2011. In early 2012, a report titled *Creating Excellence in Dementia Care: A Research Review for Ireland's National*

Dementia Strategy was published and launched by the Minister for Health Dr James Reilly at an international conference on Dementia Strategies hosted by Trinity College Dublin and the National University of Ireland, Galway. During this launch, the Minister once again reiterated the government's full commitment to the development of Ireland's Dementia Strategy by 2013 and acknowledged that the evidence base had now been well developed.

The review provides the evidence base but has not made formal recommendations about what

should be contained in the forthcoming National Dementia Strategy, as to date public consultation has not taken place. Consultation is key to any new strategy and must involve all relevant stakeholders, particularly people with dementia and their carers. Our task, based on the findings of the research review, is to identify core elements that are likely to be important in the formulation and implementation of the new Strategy.

The core elements for the new Strategy arising from the research include:

- greater emphasis on primary prevention and on ways of avoiding or delaying the illness
- enhanced public awareness about dementia
- early diagnosis through improving access to memory clinics and enhanced multi-disciplinary 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.

“We will develop a national Alzheimer’s and other dementias strategy by 2012 to increase awareness, ensure early diagnosis and intervention, and development of enhanced community based services. The strategy will be implemented over five years”

(Programme for Government, 2011-2016)



What can you do to assist in the development of Ireland's Dementia Strategy?

Policy formulation and implementation will require the direct involvement and leadership of the Department of Health in consultation with a much wider coalition of interests and stakeholders than were included in the development of the preliminary research evidence base. Given the explicit Government commitment that exists for the creation of a new Strategy and the latent goodwill that exists among stakeholders, it is a process that will take shape and gather momentum in the coming months.

We expect that you will have an opportunity to express your views and to make a contribution to this debate, either by way of submitting a written statement or through participating in a public hearing. Your voice is critical to ensuring that we get the best possible Strategy for people with dementia in Ireland. There is an opportunity now to put in place care structures and person-centred services for people with dementia and their families that will yield significant benefits, not just for care recipients but for all members of society in the coming

decades. It is up to each of us to make the most of this opportunity and help prepare a Strategy that demonstrates our enduring commitment to people with dementia and their families.

This Guide to Dementia Care in Ireland has been written to help disseminate some of the key findings emerging from the recent research review on dementia and to bring you up to date with the current facts and figures about Alzheimer's disease and the related dementias in Ireland. The Guide details the potential key elements likely to be embedded in Ireland's future Dementia Strategy and highlights the next steps for public policy development on dementia. The Guide includes a glossary of terms with definitions of key words and phrases commonly used in the context of dementia care. We hope this Guide will be useful to you.

"We expect you will have the opportunity to express your views and make a contribution to this debate by submitting a written statement or through participating in a public hearing. Your voice is critical to ensuring that we get the best possible Strategy for people with dementia in Ireland"

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Glossary of terms

Acute care

Active short-term treatment and care for an acute illness, injury or medical condition.

Alzheimer Café

A safe and relaxed place where people with dementia, their families and health and social care professionals come together for a unique blend of education and support. It is a forum where people can exchange experiences and talk about dementia.

Alzheimer's Disease

A progressive disease, in which gradually, over time, parts of the brain are damaged. It is the most common form of dementia. People with Alzheimer's disease may experience lapses in short-term memory and have problems finding the right words. As the disease progresses, the symptoms become more severe.

Anti-dementia drugs

Drugs that have been developed - particularly for Alzheimer's disease - that can temporarily alleviate some of the symptoms of dementia. There are two main types of medication used to treat Alzheimer's disease - cholinesterase inhibitors and NMDA (N-methyl d-aspartate) receptor antagonists - which work in different ways. Cholinesterase inhibitors include donepezil hydrochloride (Aricept), rivastigmine (Exelon) and galantamine (Reminyl). The NMDA receptor antagonist is memantine (Ebixa).

Anti-psychotic drugs

People with dementia may experience behavioural and psychological symptoms such as aggression and agitation, sleep disturbance, or hallucinations. Anti-psychotic drugs are a group of medications that are sometimes used to help people with dementia experiencing behavioural and psychological symptoms. However, they do have side-effects and there are a number of simple treatment and therapy options that can dramatically improve these symptoms without the need for medication. This is called person-centred care.

Assistive technologies

An umbrella term that includes a wide range of assistive, adaptive and rehabilitative devices. An assistive technology is any device or system that allows an individual to perform a task that he/she would otherwise be unable to do, or increases the ease and safety with which the task can be performed. It includes both simple devices such as calendar clocks and more high tech items such as telecare sensing. Assistive technology can promote greater independence for people with dementia and other conditions where people may experience memory problems by compensating for some of the difficulties experienced (e.g. forgetting where items have been placed or forgetting to turn off the cooker).

Carer's Allowance

A social welfare payment for people who are caring on a full-time basis for someone who requires full-time care and attention and will require it for at least 12 months. It is a means-tested payment. Responsibility for administering Carer's Allowance lies with the Department of Social Protection.

Carer's Benefit

A social insurance based payment made to insured persons in Ireland who leave the workforce to care for a person(s) in need of full-time care and attention. It is a short-term payment paid currently for a total period of 104 weeks. Responsibility for administering Carer's Benefit lies with the Department of Social Protection.

Case management

An approach whereby a professional (care manager) holds responsibility for overseeing the processes of assessment, delivery, monitoring and review of care for, and with, a patient and their family carer(s).

Challenging behaviours

Sometimes known as "behavioural and psychological symptoms" of dementia. This is where a person exhibits one or more challenging behaviours during the course of the illness. Challenging behaviours include agitation, aggression, sleep disturbance, inappropriate eating, inappropriate sexual behaviour, delusions, hallucinations and paranoia.

Cognitive impairment

A cognitive decline greater than that expected for a person's age and education level.

Community care

Personal and social care delivered in the community. Community care services including home helps, home care packages, respite care, day care.

Day care

Where people with care needs are looked after outside of their own home for short periods of time at a day care centre. At the day centre, they are offered an opportunity for psycho-social stimulus. This type of care often provides families of people with dementia with an opportunity for rest or respite.

Delirium

A complex syndrome that manifests as sudden and profound disturbances of attention, memory and behaviour. The most common factors triggering delirium are lower respiratory tract infection, urinary infection, constipation, dehydration, drugs, alcohol withdrawal and severe pain. Delirium is often reversible and amenable to treatment.

Dementia

A global or umbrella term used to describe a group of conditions or diseases that have common symptoms but different causes. Symptoms include impairments in memory, language, ability to communicate, mood and personality.

Dementia with Lewy Bodies (DLB)

A progressive disease where tiny, spherical protein deposits (Lewy bodies) present in the brain disrupt the brain's normal functioning, interrupting the action of important chemical messengers, including acetylcholine and dopamine. This form of dementia shares characteristics with both Alzheimer's and Parkinson's diseases. It accounts for about 10% of cases of dementia and appears to affect men and women equally.

Differential diagnosis

Refers to the two-stage process involved in diagnosing dementia. The first stage is to establish a diagnosis of dementia whilst the second is to elucidate the cause of the dementia (e.g. Alzheimer's disease, Vascular Dementia).

Disease burden

The impact of a health condition measured by financial cost, mortality, morbidity, or other indicators.

Down syndrome

Also known as trisomy 21, this is a genetic condition caused by the presence of all or part of an extra 21st chromosome.

Early onset dementia

Where people who are aged less than 65 years of age get dementia, also known as young onset dementia.

Formal care

Care provided by paid staff, such as nurses and care workers, working in either care settings such as hospitals or care homes or in the person's own homes.

Fronto-temporal dementia

A term covering a range of conditions, including Pick's disease, all of which are caused by damage to the frontal lobe and/or the temporal parts of the brain. These areas are responsible for our behaviour, emotional responses and language skills.

HIQA

The Health Information and Quality Authority, an independent Authority established in May 2007 to drive continuous improvement in Ireland's health and social care services. HIQA is the regulatory, standard-setting and inspection body for residential care settings.

Home Care Packages

Formally known as the Home Care Support Scheme, this is one of the key measures in place in Ireland to support older people with care needs, including those with dementia, to remain living in their own homes for as long as possible.

Long-Stay Activity Statistics

Statistics collated by the Department of Health on the number of beds available for long-term care, how the beds are used and the types of patients who occupy these beds. They are issued on an annual basis.

Long-stay residential care

Public, private and voluntary services providing care to people usually on a permanent basis outside of their own home in an institutional setting. Long-stay residential care in Ireland tends to be synonymous with nursing home care.

Memory aids

Devices available to help people who have problems with their memory such as calendar clocks.

Memory Clinics

Clinics primarily aimed at identifying, investigating, diagnosing and treating memory problems/disorders, including dementia.

Mild Cognitive Impairment

Mild cognitive impairment (MCI) is a relatively recent term, used to describe people who have some problems with their memory but do not actually have dementia.

Mortality rate

A measure of the number of deaths in a population, scaled to the size of that population, per unit of time.

Prevalence of dementia

Refers to the number of cases of dementia in a given population at a certain time.

Primary care

Refers to the first point of contact that people generally have with health services. In Ireland, this contact is usually with GPs. Other professionals such as public health nurses also deliver primary health care. The services and resources available within the primary care setting have the potential to prevent the development of conditions which might later require the input of secondary services or hospitalisation.

Respite care

Also known as short breaks; refers to short-term placement in some form of residential setting or alternatively care provided in the home to afford family caregivers a short break.

Secondary services

Refers to specialist services, which may be community-based 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 dementia, Geriatric Medicine, Old Age Psychiatry, Neurological services are examples of secondary care services.

Specialist Care Units

Small-scale home-like units creatively designed to make it easier to provide good care for people with dementia and with staff specially trained in dementia care.

Stigma

The disapproval or labelling of a person on the grounds of characteristics that distinguish him/her from other members of society.

Teaghlach model of care

Developed to drive a change in culture in residential care settings from a focus on tasks to one which supports residents to continue to direct their own lives supported by consistent and valued teams of care staff. The aim of this model is to develop residential care settings that are home-like in all respects. It is sometimes referred to as the household model of care.

Vascular Dementia

Vascular dementia is caused by problems in the supply of blood to the brain. It is the second most common form of dementia after Alzheimer's disease. Vascular dementia affects different people in different ways and the speed of the progression varies from person to person.

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Relevant and useful websites

The Alzheimer Society of Ireland
www.alzheimer.ie

The Alzheimer Café
www.alzheimercafe.ie

Alzheimer Disease International
www.alz.co.uk

Alzheimer Europe
www.alzheimer-europe.org

**Dementia Services Information
and Development Centre**
www.dementia.ie

Department of Health
www.dohc.ie

Department of Social Protection
www.welfare.ie

Genio Dementia Project
www.genio.ie

Health Information and Quality Authority
www.hiqa.ie

Health Service Executive
www.hse.ie

Irish Centre for Social Gerontology, NUI Galway
www.icsg.ie

Living with Dementia programme, TCD
livingwithdementia.tcd.ie

The Atlantic Philanthropies
www.atlanticphilanthropies.ie



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