

C|A|R|D|I **GRANTS**
PROGRAMME

Research Brief

**A comparison of people
seeking help at memory
clinics in Belfast and
Dublin**

Facts on dementia – ROI

- There are currently around 41,740 people with dementia, with the numbers expected to grow to between 141,000 and 147,000 by 2041.
- There are nearly 50,000 people in ROI who are involved in caring for someone with dementia. Family carers provide 57% of the value of informal care.
- The baseline cost of dementia in ROI is estimated at €400m.

Facts on dementia – NI

- There are currently around 19,000 people with dementia in NI. It is expected there will be 23,000 people with dementia by 2017 and 60,000 by 2051.
- It is estimated around 1,400 deaths a year are directly attributable to dementia. These deaths could be reduced by half if the onset of dementia could be delayed by five years.
- Two thirds of people with dementia live in the community while one third live in a care home.

Dementia policy – ROI

- The ROI government intended to develop a national dementia strategy in 2010 but this has not yet been published.
- A Vision for Change (2006) is the strategic policy document for mental health in general. It makes 14 recommendations on the subject of mental health and older people.
- 6% of total public health expenditure is spent on mental health in the ROI.

Dementia policy - NI

- A dementia strategy for NI, Improving Dementia Services in Northern Ireland, was published in November 2011.
- Mental health, including dementia, is the responsibility of the Department of Health, Social Services & Public Services.
- 8.4% of total public health expenditure is spent on mental health in NI.

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Introduction

The precise incidence (new occurrences) and prevalence (total number of cases) of dementia in ROI is unknown, in part due to difficulties with defining and detecting dementia in its early stages (Jorm et al., 1987). Dementia refers to a group of diseases characterised by a progressive and generally irreversible decline in mental functioning, predominantly affecting people over the age of 65. It is a major social and economic challenge for countries with ageing populations as growing numbers of people are living to an age when dementia is likely to occur.

In 2011, CARDI funded a project led by Dr. Suzanne Barrett of the Centre for Public Health, Queen's University Belfast, which aimed to examine and compare some of the characteristics of people seeking help at memory clinics in Belfast and Dublin. *A Comparison of People Presenting with Symptoms of Dementia in Northern Ireland and the Republic of Ireland* (Barrett, et al., 2012) looked at two memory clinics, the Belfast City Hospital Clinic in Northern Ireland (NI) and the Mercer's Memory Clinic at St. James's Hospital, Dublin, in the Republic of Ireland (ROI). This research brief is based on the findings of the project, conducted as part of CARDI's data mining programme, as well as additional research on the context of dementia care and diagnosis across the island of Ireland.

Key findings

- Early diagnosis of dementia is crucial as some treatments are more effective in the early stages. Earlier diagnosis and timely intervention also provide health, financial and social benefits (Alzheimer's Disease International, 2011).
- Belfast City Hospital and Mercer's Memory Clinic Dublin case study¹ key findings:
 - In 1998-1999, people receiving a diagnosis of AD in both the Belfast and Dublin clinics were predominantly female. More recent data from the Dublin clinic show the sex disparity decreasing and now approaching 1:1 (Barrett, et al., 2012).
 - The mean age of diagnosis with AD in the Dublin clinic for the period 2003-2006 was 74, compared to 78 in the Belfast clinic. The age at diagnosis in Dublin has fallen by approximately 2.5 years compared to 1998-1999 (Barrett, et al., 2012).
 - People diagnosed in Dublin were more likely to be taking an AChE inhibitor or lipid-lowering drug, whereas patients in Belfast were more likely to be taking anti-anginal or anti-platelet drugs (Barrett, et al., 2012).

1 The case study is not intended to be representative of memory clinics across NI or ROI.

Dementia detection and prevalence in Ireland

A recent estimate suggests that there are currently 41,740 people with dementia in the ROI. Around 26,104 of these people live at home in the community, and most of these do not have a formal diagnosis, while 14,266 live in various public and private long-stay facilities across the country. The same research suggests that 63% of all residents in long-stay care have dementia (Cahill et al., 2012).

Raw clinical prevalence rates are available in NI as a result of the Quality and Outcomes Framework (QOF), a product of the GP contract introduced in the UK in 2004. The prevalence was 5.71 for 2009/10 and 5.97 for 2010/11 per 1,000 population (Tesco, Alzheimer Society and Alzheimer Scotland, 2011). The NI strategy for dementia published in 2011 estimates that there are 19,000 people with dementia, fewer than 1,000 of whom are younger than 65 (DHSS&PS, 2011). The Belfast Health and Social Care Trust is ranked number one out of 169 Health Boards in the UK, having the lowest estimate for undiagnosed cases of dementia (31%) (Tesco, Alzheimer Society and Alzheimer Scotland, 2011).

The prevalence of dementia increases almost exponentially as we grow older, nearly doubling every five years (Qiu et al., 2009). In contrast to other forms of dementia, early-onset familial AD, usually occurring before the age of 65, is rare, accounting for between 4-5% of all cases. The increase in the prevalence of dementia is steeper for females, for whom prevalence is much greater in the oldest age categories. In addition to age, other known predictors of dementia include:

- Positive APOE4 genotype².
- Cardiovascular compromise.
- Low education level.
- Prior diagnosis of mild cognitive impairment (MCI) (Barrett, et al., 2012).

MCI is a relatively new diagnosis, considered by many to be a transitional state between normal age-related memory decline and dementia. A MCI patient experiences memory decline to a greater extent than would be expected for normal ageing, but does not fit the currently defined clinical criteria for AD. The criteria for MCI diagnosis are that there is a subjective memory complaint, objective memory impairment, intact functional domains and that the patient is not demented (Petersen, 2011). A recent cross-sectional epidemiological study estimated the prevalence of MCI at 2.27% (Ganguli et al., 2010).

2 Having the E4 variant of the Apolipoprotein E gene.

GPs

Despite differences in the health systems, the GP is the first port of call and a pivotal health professional contact for the majority of people with dementia in both ROI and NI. In ROI, diagnosis of dementia is generally conducted through primary care services and less frequently in memory clinics or community based services for older people (Cahill, 2010). In NI, GPs are encouraged to both detect and review cases of dementia. They are financially rewarded for setting up a register of people with a diagnosis of dementia and for subsequently monitoring their care (DHSS&PS, 2011).

Memory clinics

Memory Clinics were first established in the US in the 1970s, where Alzheimer's disease research centres offered outpatient diagnostic, treatment and advice services for people concerned about memory problems. In the UK, the first memory clinic was opened in St Pancras Hospital in London in 1983. In ROI, the first memory clinic opened at St James's Hospital in 1991. There are currently 13 memory clinics operating in ROI: six are based in Dublin, two in Cork and others in Navan, Mullingar, Cashel, Carlow and Galway (Irish Medical Times, 2011). In NI, the strategy for dementia services published in 2011 states that all five Health and Social Care Trusts have memory services available. It outlines the principles by which a memory service should operate for people with problems, summarised in Table 1.

Table 1: Principles of a memory service (NI dementia strategy)

Accessible to people with memory problems and their carers.
Designed and managed so that the respect and dignity of people with memory problems/dementia and their carers is preserved.
Staff work effectively as a multidisciplinary team.
Sufficient numbers of appropriately skilled and qualified staff for their jobs, and their continuing professional development is facilitated.
Works closely with other professionals, agencies and providers to support the processes of assessment and diagnosis.
Offers a range of supports to promote early identification and referral into the service.
Any clinic run is accommodated in an environment that is appropriate to the needs of people with memory problems/dementia.
Any clinic run provides the necessary facilities and resources for staff to effectively carry out their duties.
Provides timely access to assessment and diagnosis.
Staff follow clear procedures for gaining consent and ensure that people with memory problems/dementia are well-informed of their rights regarding consent.
Personal information is kept confidential unless this is detrimental to the person's care.
The outcome of the assessment is communicated to all relevant parties in a timely manner.
Able to offer appropriate advice, information and support, including counselling, to people with memory problems/dementia and their carers at the time of assessment and diagnosis.
Professionals working within the memory service ensure that the person (and their carer, where appropriate) is able to access a range of post-diagnostic supports and interventions, including counselling.
Ensures that each person with memory problems/dementia is followed up.

Source: Royal College of Psychiatrists, quoted in DHSS&PS (2011)

Early diagnosis and dementia

Diagnosis of dementia is the gateway for care and management of the disease. Before a diagnosis is made, no drug or non-drug treatment can be given or future care planned. There are marked differences between countries in the rate of diagnosis, rate of treatment, roles played by families and in the care provided by formal health and social services. However, there is consensus that diagnosis should be made as early as possible to enable patients with dementia and their families to benefit from those interventions that are currently available (Knapp et al., 2007).

The Organisation for Economic Co-operation and Development (OECD) conducted a study of dementia services across nine countries in 2004 which found that large proportions of people with dementia do not receive any diagnosis, let alone an early diagnosis. This led to the introduction of new policy frameworks in some countries, such as the UK National Service Framework for Older People, which focus on the importance of early detection of dementia to help patients and their families prepare for the future in terms of care arrangements and for the person with dementia to express their choices for the future (Moise et al., 2004).

In the OECD study, memory clinics were found to be operating in all of the countries, but the balance between clinical work and research varied. It also found that the capacity to meet the need for diagnosis in the areas served by memory clinics has not been investigated. Finally, the study found that clinics appear to reach only a very small proportion of people with dementia in any country (Moise et al., 2004).

International research shows that most people currently living with dementia have not received a formal diagnosis. In high income countries, only 20-50% of dementia cases are recognised and documented in primary care. The situation is even more serious in low and middle income countries, with one study in India suggesting 90% of cases remain unidentified (Alzheimer's Disease International, 2011).

In order to facilitate early diagnosis, Alzheimer's Disease International identifies three steps that can be taken by governments and health systems which could help to improve the likelihood of earlier diagnosis of dementia:

1. Medical practice-based educational programs in primary care.
2. Introduction of accessible diagnostic and early stage dementia care services (memory clinics are one example of these).
3. Promoting effective interaction between different components of the health system (Alzheimer's Disease International, 2011).

A case study of two memory clinics Belfast and Dublin³

The Mercer's memory clinic in Dublin and the memory clinic at Belfast City Hospital provide specialised services for people with memory loss and dementia across the island of Ireland. As part of the clinical services offered, they provide an assessment and diagnostic service to clients with cognitive deficits, as well as interventions for people concerned about changes in their memory. Both services attempt to work closely with primary carers in recognition of the fact that the main bulk of care in both regions is undertaken by the families of dementia sufferers (Barrett, et al., 2012). Barrett, et al (2012) conducted a review of the characteristics of people diagnosed in both clinics with MCI and AD in order to provide a case study of two memory clinics. It is important to note that both clinics operate in distinct healthcare systems.

Characteristics of Alzheimer's disease patients at the two case study clinics

- In 1998-1999, people diagnosed with AD in both Belfast and Dublin were predominantly female, outnumbering males by approximately five to two. Those diagnosed in Dublin were significantly younger than their Belfast counterparts.
- The educational attainment of people diagnosed in Belfast was found to be significantly lower than in the Mercer's memory clinic⁴.
- The Mini-Mental State Examination (MMSE) scores improved by over 2.5 points between 1999 and 2007 in both clinics. MMSE scores were also over two points lower in the Belfast centre at both of the time points examined.
- More recent data from 2009-2011 for the Dublin clinic shows that the sex disparity between males and females diagnosed has reduced, with the ratio now approaching 1:1. The age at diagnosis has fallen by approximately 2.5 years compared to 1998-1999.

Characteristics of Mild Cognitive Impairment patients

- In 2008-2010, people receiving a diagnosis of MCI were somewhat more likely to be female in Dublin (approximately 2:3) but the ratio was close to 1:1 in Belfast.
- Those diagnosed with MCI in Belfast were approximately three years older and had a lower educational attainment than patients in Dublin: 53% reported education to primary school level compared to 43% in Dublin.

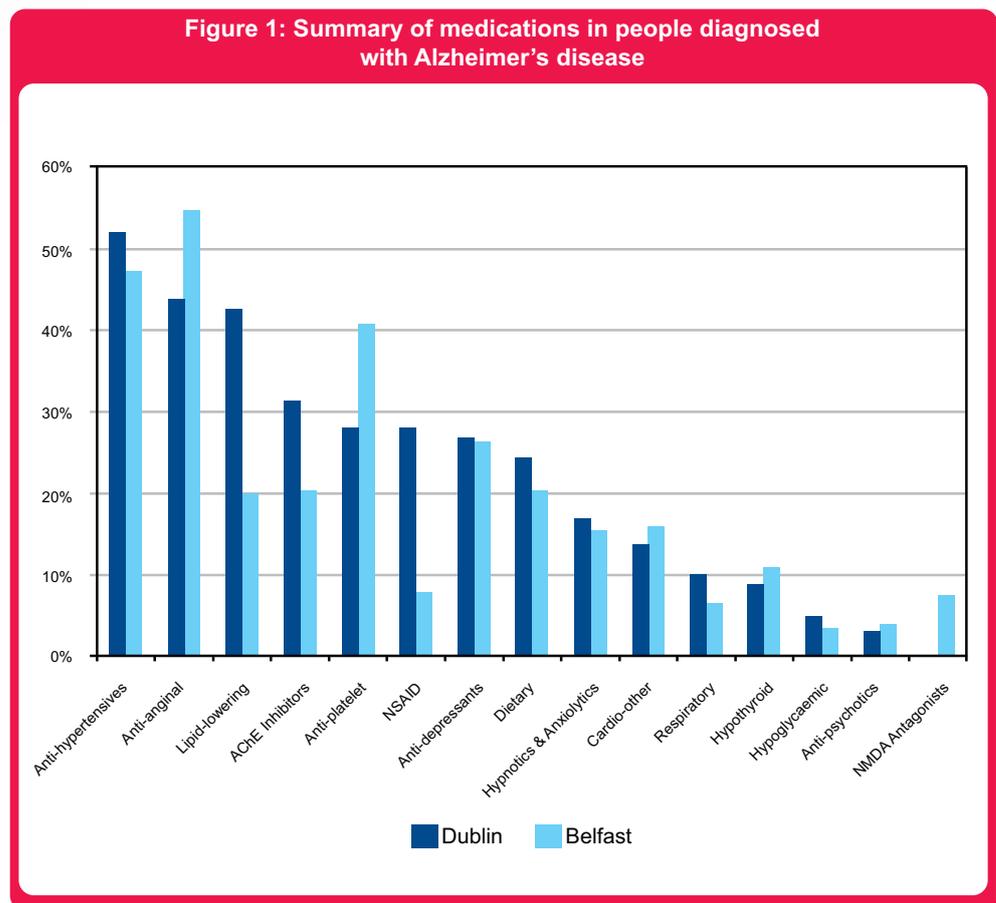
3 The project analysed data from 888 people diagnosed with MCI and 663 diagnosed with probable AD spanning the time period January 1998 to December 2010. Datasets from ROI and NI were examined for all common variables and the ones extracted were age at diagnosis, gender, education level, MMSE score and Controlled Oral Word Association Test verbal fluency scores. Comparisons between the Dublin and Belfast clinics were made using chi-squared tests for frequency data; independent samples t-tests for continuous data; and Analysis of Variance tests where cross-sectional and longitudinal data were available.

4 There can be many factors accounting for this difference, including the social economic background among people who attend a clinic in a particular area.

- Patients diagnosed with MCI in Belfast outperformed the ones in Dublin on comparable neurocognitive assessments, including by an approximate average of three points on the MMSE⁵.
- The number of individuals diagnosed with MCI has increased dramatically in the Dublin clinic between 2002-2004 and 2008-2010, with an approximate fourfold increase in the numbers. The age of people receiving this diagnosis has been decreasing over time, by approximately three years from 2002 to the end of 2010.

Medications of patients at diagnosis

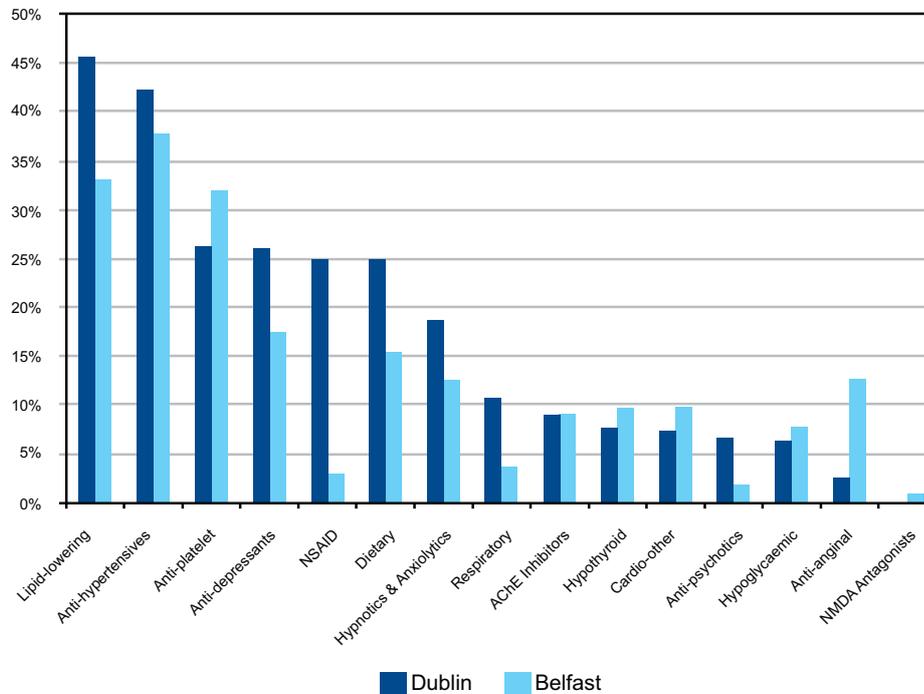
Barrett et al (2012) examined the medications prescribed to patients with MCI and AD in Belfast and Dublin to see if there was any evidence of different practices. In Belfast, data is available for both before and after the initial visit to the memory clinic, whereas in Dublin this data is combined.



Source: Barrett et al (2012)

⁵ Factors influencing this finding are different assessment procedures, changes in the number of referrals that fall within this category and latterly, redirection of people with MCI to an ongoing study in the Mercer's Memory Clinic.

Figure 2: Summary of medications in people diagnosed with MCI



Source: Barrett et al (2012)

- Anti-dementia medications:** Those diagnosed with AD in Dublin were more likely to be receiving an AChE inhibitor, 31.25% compared to 20.4% in Belfast. There was no prescribing of an NMDA antagonist in Dublin, while 7.5% of those diagnosed in Belfast were prescribed this medication after the initial visit. For patients diagnosed with MCI, those in Dublin were much more likely to be receiving an AChE inhibitor, 9% compared to none in Belfast at this early stage.
- Cardiovascular-related medications:** Patients diagnosed with AD in Belfast were less likely to be taking a lipid-lowering agent than those in Dublin, 19.9% compared to 42.5%. At the same time, those in Belfast were more likely to be receiving anti-platelet drugs, 40.8% in Belfast compared to 28.1% in Dublin.
- Psychiatric drugs:** Levels of prescribing for patients with AD for psychiatric drugs were found to be very similar while there was a general trend toward more psychiatric prescribing for MCI patients in Dublin than in Belfast. This was most significant for anti-psychotic drugs, with 6.7% of patients prescribed these in Dublin compared to 1.9% in Belfast.
- Other medications and supplements:** Significantly more people were prescribed non-steroidal anti-inflammatory drugs (NSAID) in Dublin (28.1%) than in Belfast (8%). For MCI patients, there was more prescription of respiratory drugs, NSAIDs and dietary supplements in the Dublin clinic.

Implications of the research

Gender differences

Traditionally, there has been a greater number of females than males receiving a diagnosis of AD in both the Belfast and Dublin clinics. At the same time, the gender distribution for MCI is generally closer to 1:1. It is often thought that the gender differences observed for AD reflect the fact that males are generally less likely to reach the age at which the disease is most likely to develop. This is reflected in the increase in the prevalence of dementia with age, which is steeper for females, for whom prevalence is much greater in the oldest age categories (Qiu et al., 2009). It is notable that the age at which people are being diagnosed with MCI is much younger than for AD for both the Belfast and Dublin memory clinics. The most recent data from Dublin suggests that the gender disparity for AD may be declining. The age at which people are receiving a diagnosis of MCI and AD has been falling in the Dublin clinic and it is possible that as dementia cases are being detected earlier and referred into the service, possibly with suspected MCI, more male cases of AD are being uncovered, thus accounting for this shift in the gender distribution of new cases of AD.

Level of education

The level of educational attainment of patients referred to the Dublin clinic has been shifting from primary level only to a more even split across levels of education. This is in contrast to the Belfast clinic, which continues to see a higher proportion of people with both AD and MCI who have had a primary school education only. This could indicate that secondary health provision for dementia in the Mercer's memory clinic case study attracts higher socio-economic groups (who have higher levels of education) and also males, although shifts over time in the socio-demographics of the respective population at risk cannot be discounted (Barrett, et al., 2012).

Level of cognitive impairment

Mean MMSE scores have been relatively static in the Dublin clinic, despite factors such as the increase in MCI diagnosis and a fall in the average age of patients diagnosed. This suggests that the diagnosis of MCI may be more conservatively provided in Dublin.

Medications

The data suggest that people with suspected dementia in the ROI case study are more likely to begin a drug treatment for dementia at a very early stage. Historical data also show that a later presentation for AD is likely to affect "anti-dementia" drug-prescribing patterns, shifting from a preference for AChE inhibitors in milder AD (Belfast and Dublin) to NMDA antagonists where moderate disease is being more commonly encountered (Belfast). Patterns of prescribing are also different between NI and ROI with regards to cardiovascular-related medications. Differences are likely to reflect, in part, GP prescribing rights with regards to anti-dementia drugs as well as how healthcare providers are approaching prevention of cardiovascular disease. There appears to be a lower level of prescribing for all medications in people referred for dementia assessment in Belfast.

Policy contexts, North and South

NI

In NI, dementia and all other mental health issues fall under the remit of the Department of Health, Social Services and Public Safety. It published a dementia strategy in November 2011 entitled *Improving Dementia Services in Northern Ireland – A Regional Strategy* (DHSS&PS, 2011). The overall aim of the strategy is to reduce the risk or delay the onset of dementia in the NI population while raising dementia awareness. The strategy stresses the importance of an early and accurate diagnosis when it comes to dementia and states that it has been estimated that delaying the onset of dementia by five years could halve its prevalence. It also raises the issue of proper and effective medication use, particularly the use of antipsychotics which can have negative side effects.

ROI

In ROI, the Department of Health has a dedicated Office for Disability and Mental Health with responsibility for dementia issues. The National Council on Ageing and Older People published an action plan on dementia in 1999 (National Council on Ageing and Older People, 1999) and a strategic policy document for mental health in general, *A Vision for Change*, was published in 2006 (Department of Health and Children, 2006). However, progress on implementing mental health policy has been slow and a dedicated dementia strategy is yet to be published. In 2012, an extensive research review on dementia, *Creating Excellence in Dementia Care*, was published (Cahill et al., 2012). It lays the foundations for a new dementia strategy in ROI, identifying current gaps in service provision and examining the action plans of other countries on dementia.

Conclusion

With rising numbers of people with dementia across the island of Ireland, reducing the risk of dementia by raising awareness of the risk factors and delaying the onset of the disease should be key priorities. As part of this, sharing information across health services, such as between NI and ROI, is essential. This can help to develop best practice in terms of early diagnosis, medication and treatment for people with dementia.

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Bibliography

Alzheimer's Disease International. (2011). *World Alzheimer Report 2011: The benefits of early diagnosis and intervention.*

Alzheimer's Society. (2007). *Dementia UK Northern Ireland Supplement: The Rising Cost of Dementia in the UK.*

Barrett, S. et al. (2012). *A Comparison of People Presenting with Symptoms of Dementia in Northern Ireland and the Republic of Ireland.* Centre for Ageing Research and Development in Ireland.

Cahill, S. (2010). Developing a National Dementia Strategy for Ireland. *International Journal of Geriatric Psychiatry* 25 , 912-916.

Cahill, S., & Maher, L. (2011). *Memory Clinics in Ireland: A Guide for Family Caregivers and Health Service Professionals.*

Cahill, S., O'Shea, E., & Pierce, M. (2012). *Creating Excellence in Dementia Care: A Research Review for Ireland's National Dementia Strategy.*

Department of Health and Children. (2006). "A Vision for Change": *Report of the Expert Group on Mental Health Policy.*

DHSS&PS. (2011). *GP contract (accessed online).*

DHSS&PS. (2011). *Improving Dementia Services in Northern Ireland - A Regional Strategy.*

Ganguli, M., Chang, C., Sinitz, B., Saxton, J., Vanderbilt, J., & Lee, C. (2010). Prevalence of mild cognitive impairment by multiple classifications: The Monongahela-Youghiogheny healthy ageing team project. *American Journal of Geriatric Psychiatry* 18(8) , 674-683.

Irish Medical Times. (2011, May 16). Retrieved from Keeping Memory in Mind.

Jorm, A., Korten, A., & Henderson, A. (1987). The prevalence of dementia: A quantitative integration of the literature. *Acta Psychiatrica Scandinavica* 76, 465-479.

Knapp, M., Comas-Herrera, A., Somani, A., & Banerjee, S. (2007). *Dementia: International Comparisons.* London School of Economics and King's College London.

Moise, P., Schwarzinger, M., & Um, M. (2004). *Dementia Care in 9 OECD Countries: A Comparative Analysis.* Paris: OECD.

National Council on Ageing and Older People. (1999). *An Action Plan on Dementia.*

O'Shea, E. (2007). *Implementing Policy for Dementia Care in Ireland: The Time for Action is Now.* Dublin: The Alzheimer Society of Ireland.

Petersen, R. (2011). Mild Cognitive Impairment. *New England Journal of Medicine* 364 , 2227-2234.

Petersen, R., Doody, R., Kurz, A., Mohs, R., Morris, J., Rabins, P., et al. (2001). Current concepts in mild cognitive impairment. *Archive of Neurology* 58 , 1985-1992.

Qiu, C., Kivipelto, M., & Von Strauss, E. (2009). Epidemiology of Alzheimer's disease: occurrence, determinants and strategies toward intervention. *Dialogues in Clinical Neuroscience* 11(2) , 111-28.

Tesco, Alzheimer Society and Alzheimer Scotland. (2011). *Mapping the Dementia Gap Study.*