

# An Economic Perspective of Dementia Care in Ireland:

## Maximising Benefits and Maintaining Cost Efficiency

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This report gratefully acknowledges funding from the Irish Research Council for Humanities and Social Sciences



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*“Parallels can be drawn between dementia now and cancer in the 1950s, when there were few treatments and patients were commonly not told the diagnosis for fear of distress.” Comptroller and Auditor General, National Audit Office, 2007*

## Introduction

Dementia is a major health issue and a global condition. Increasing prevalence, costs and burden of disease assert significant pressure on economic and social systems in many countries. Globally costs for people with dementia amount to more than 1% of gross domestic product (GDP)[1].

Concurrently, the World Health Organisation [2] observes a growing gap between budget allocation and the associated burden of mental health disorders, particularly in higher income countries. Point in care, the economic burden of dementia ranks higher than stroke, heart disease and cancer combined [3], however health care allocations for dementia continue to be substantially lower than each of these individual disease groups.

Given the multiple agents who are involved in dementia care, ascertaining expenditure has inherent difficulties. A common indicator is investment on long term care, which is the composite of institutional and community based home care. Figure 1 compares spend (as a percentage of GDP) on long term care for both public and private sectors[4]. In terms of percentage of GDP, Ireland spends approximately half the OECD average. More importantly, UK, Canada and Australia where dementia specific strategies have been implemented shows show sizable differences.

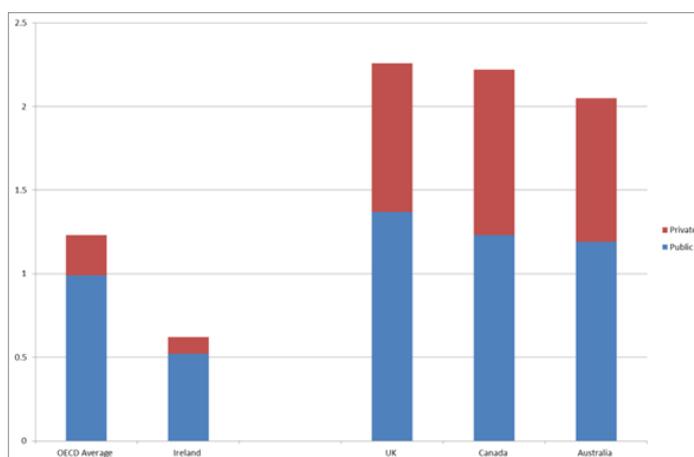


Figure 1: OECD, 2007 [4]

Ireland is predicted to have the largest growth in the older population of all European countries in the coming decades[5]. In real terms, the population is predicted to increase threefold and with this so will the demand for dementia specific services. Given the prognosis of dementia combined with predicted economic impacts, the WHO indicate that the key priority for dementia is targeted interventions towards the carer[6].

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## International evidence

International evidence can aid prioritisation on spending in a manner which will maximise benefits to society whilst maintaining optimal cost efficiency. Ireland faces many challenges and choices in relation to investment in dementia care. The evidence is presented in three themes:

1. Prevention
2. Care
3. Cure.

Systematic reviews seek to collate all evidence to minimise bias by using explicit, systematic methods [7]. Therefore for each theme, relevant systematic reviews are presented and where possible inferences are made in relation to the associated cost-benefit positive strategies.

### Prevention is one step before early diagnosis

The detection of dementia in community settings can be challenging[8]. In a survey of Irish GPs, the most commonly reported barriers to diagnosis were the differentiation from the normal ageing process (31%), lack of confidence (30%) and fear the impact of the diagnosis (29%). As such only 19% stated they often or always disclosed a diagnosis. Given that the most commonly used instruments have come under question[9], perhaps this reluctance is understandable and therefore the diagnostic accuracy of screening instruments have been reviewed[10].

Some of current thinking is that prevention may be one step before early diagnosis, through targeting those with mild cognitive impairments (MCI). Risk factors would suggest that 12-15% of people with MCI progress to Alzheimer's disease or at least to a non-specific dementia [11], compared to a rate of 1-2% in healthy adults. The viability of self-referral memory clinics are being piloted for their role in detecting MCI. Various reviews of research indicate potential strategies:

- Cognitive interventions [12]
- Chinese medicines [13]
- Gingko [14]
- Physical activity [15]
- Cholinesterase inhibitors [16]
- Vitamins: B6[17], B12[18], E [19]

The Canadian Alzheimer's Society simulated scenarios for prevention by addressing risk factors[20]. For example, aged 65 plus could significantly reduce the number of diagnosis by increasing their exercise rate by 50% [21]. The impact of delaying onset of dementia by two years was also simulated [22]and results would suggest that reduction of numbers of people living with dementia would be up to 36.4% which would equate to saving of \$218billion.

## Dementia Care in Ireland

### An international Comparison

Adequate preventative measures are still outstanding so the focus returns to the care and the service infrastructure. As the WHO report suggests the carer plays a critical role in dementia and is the focus of much debate.

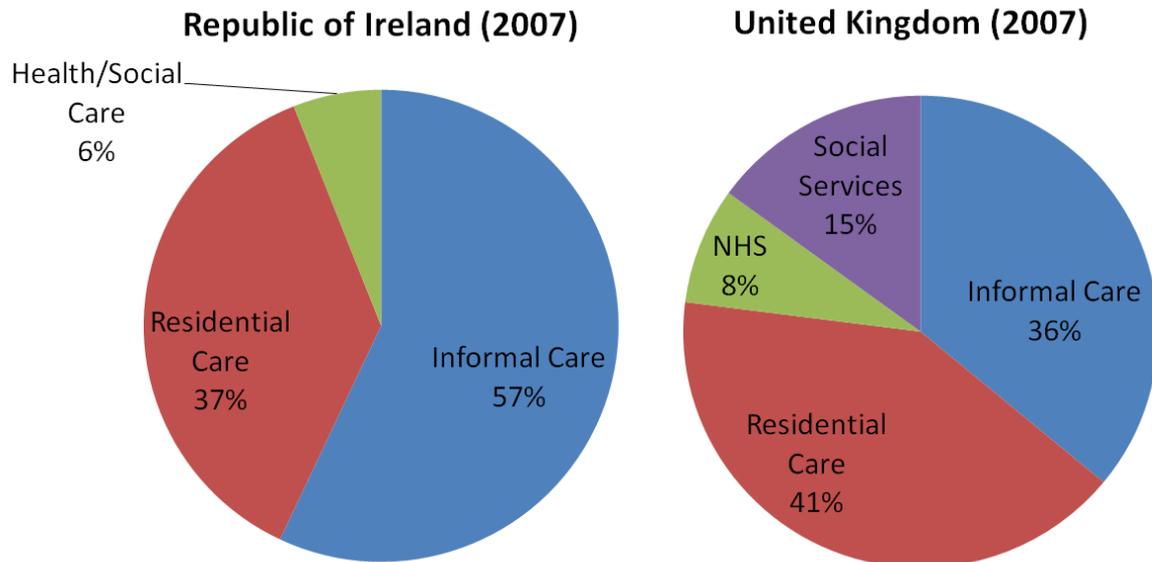


Figure 2: Distribution of Care Related Costs by Country (Ireland: O'Shea, 2007[23]; United Kingdom: Dementia UK, 2007[24])

Figure 2 highlights Ireland's greater reliance on informal care than in the United Kingdom. With the presence of health and social care at 23%, in the UK we note a substantially less economic burden placed on families. O'Shea [23] estimates the value of informal care using a modest opportunity cost method and indicates that the proportion of cost associated to informal carer would rise to 76% if productivity loss (at national minimum wage) were also incorporated. These comparative cost distributions point toward Ireland's high level of carer burden being associated to subordinate investment in formal care.

Dementia UK [24] further elaborates on this picture by associating annual costs of care by severity of disease and setting. This reveals that while levels of formal care (NHS and Social) remain relatively flat during dementia progression, reliance increases on the informal carer (see figure 3).

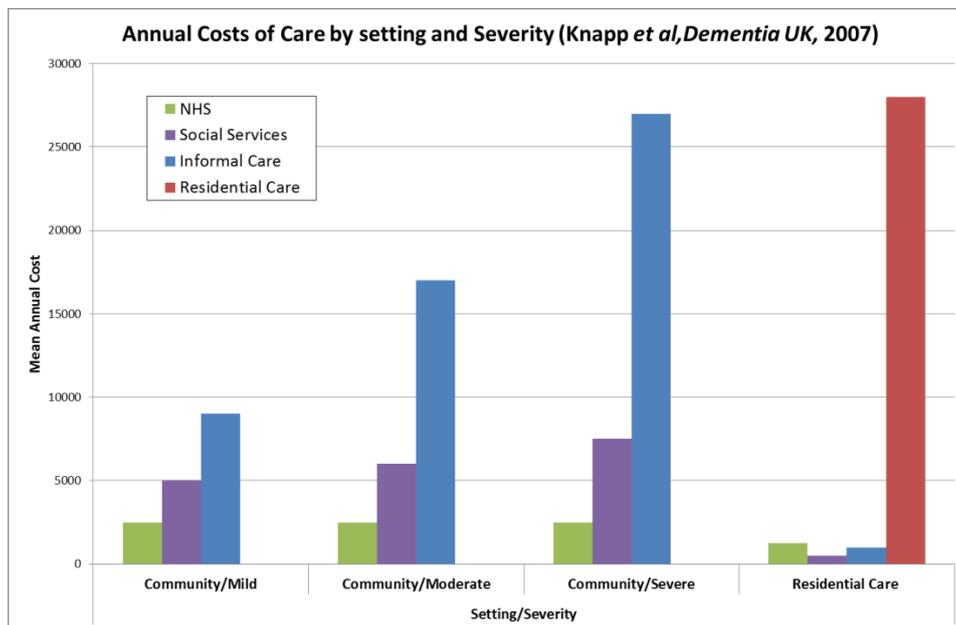


Figure 3: Knapp, Prince *et al*, Dementia UK, 2007

An Irish survey of 270 carers of people with dementia confirms that increasing informal costs are associated with disease progression and are present in Ireland. The average number of hours per day spent caring as the dementia progressed rise from 7.18 hours in the early stage to 13.15 hours during the late stages. Valuing this time using replacement cost estimate of a care assistant (€33.62 per hour) would approximate the value for one day of care from €242 per day in early stages to €442 in late stages[25].

Further analysis finds that sixty-three percent of respondents were below retirement age and analysis of this subgroup revealed that as a result of caregiving, half stopped working to care; of those in fulltime employment, 61% reduced working hours, and 71% of carers in part-time employment reduced it to below 20 hours per week. These findings are consistent with several other studies associated with a reduction in employment rates with informal caregiving. Spiess & Schneider [26] noted that north European women who start or increase informal care showed a reduction in working hours. Henz, [27] found that a third of carers reported a disrupted work routine commonly resulting in stopping working.

This level of carer burden is avoidable through appropriate service and intervention. For example, Schoenmakers *et al* [28] systematically reviews seven randomised control trials, (n=3,424) showing a small but statistically significant change in carer burden through drug treatment and concludes that the first line should be in assisting the carer to cope in their new role.

## The critical carer

*“It is one of the truly heart-warming things about Alzheimer’s that so many partners and offspring quietly take on another’s chores and devote themselves, quite selflessly, to the care of someone they love.”*

Hampson (2000), p54[29]

Caring for a family member or relative has been referred to as the “hidden patient”[30] and the carer often experiences adverse physical, mental and social outcomes. Caregiver burnout therefore presents a significant and immediate threat to the balance of care for people with dementia. Various studies [31-34] have associated burnout to emotional exhaustion, decreased personal accomplishment and depersonalisation (an uncaring reaction towards care-recipient).

The Irish survey indicates that of the individuals caring for a person in middle to late stages of dementia, 69% will be providing 14 or more hours per day of care. This presents a significant risk of burnout due to overload and therefore the need for interventions directed to the carer [33].

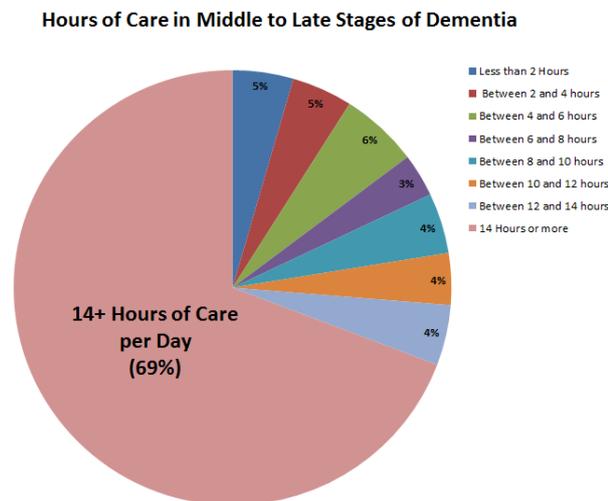


Figure 4: Trepel *et al*, 2010[35]

## Care for your carers

Cost-effectiveness research of carer directed interventions is limited but two main studies are cited:

- Gaugler, Jarrott *et al*. [36] found that intervention groups accessing subsidised adult day care at least twice per week reduced role overload and depression. Results show an encouraging incremental cost-effectiveness ratio over the control group not receiving day care. Importantly this study concludes that dementia caregivers who use these services consistently and for longer periods of time maximise effectiveness and optimal gains are produced by encouraging early utilization of services during the caregiving career to increase the range of benefits.
- Donaldson and Gregson [37] conducted an economic evaluation of community support initiatives that provided day and respite care. They found that despite additional costs of service, day care was cost-effective in part by observed savings accrued in reduced long-term beds utilisation.

To give greater statistical power and robustness in evaluating such intervention the gold standard in health economic evaluation is to use meta-analysis of several randomised control trials. Pinquart *et al* [38] collected systematic evidence on the effectiveness of interventions for carers, reviewing 127 studies (containing approximately 5,930 participants).

Interventions include:

- **Psychoeducation:** Structured training for carer (e.g. role play)
- **General support:** Informal support groups
- **Respite:** Planned, temporary relief for caregivers (inclusive of daycare, in-home and respite)
- **Cognitive behavioural therapy:** Developing behavioural repertoire for caregiving
- **Counselling:** Dealing with family conflict with relevance to the carer role.

Results from the meta-analysis show interventions in the following domains-specific outcomes:

1. Reduction in burden;
2. Reduction in levels of depression;
3. Increases in subjective well-being;
4. Increased ability/knowledge;
5. Improvement of symptoms of care recipient.

Furthermore, combinations of interventions were associated with a reduced risk of patient institutionalisation, particularly where “lasting changes in the lives of the caregivers” were made. Pinquart concluded that the approach should be tailored to suit the specific needs of the caregiver and that future research should investigate combinations of interventions to increase the effectiveness on the varying outcomes.

In summary, the above evidence points to two risks imposed on carers in their role which should be considered when allocating resources for their support. Carers are most likely to reject the role during early stages of caring therefore early intervention is important; and duration of care giving is longer where the carer receives formal interventions.

## The Cure

The multi-causal characteristics of dementias means that cures may be represented by a continuum of outcomes ranging from improved quality of life, significant symptoms control, retarded onset and even disease reversal.

In 2008, government investment in Ireland on health related research was €199 million per annum [39]. Data provided by three leading public health-research funding bodies (Figure 5), estimated 2.58% of the total could be attributed to dementia specific research.

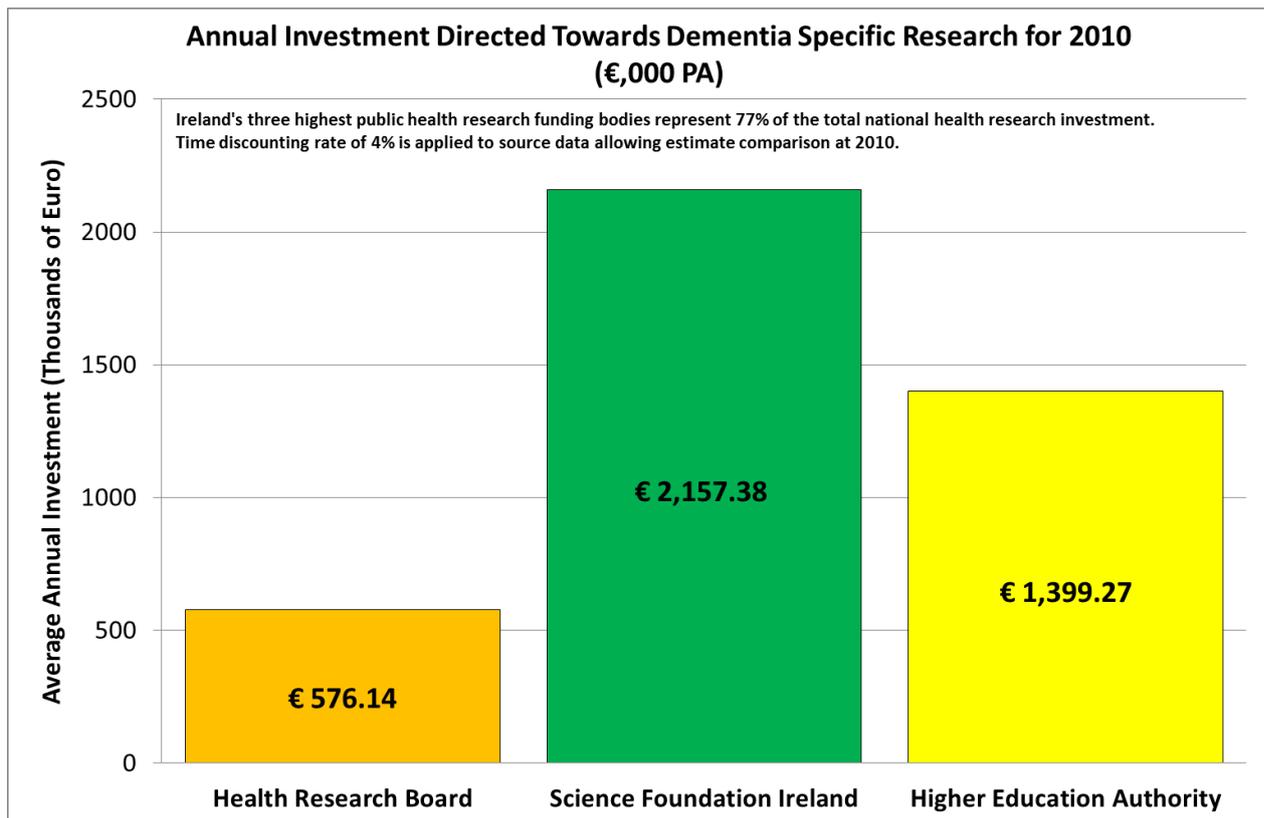


Figure 5: Estimated Total Annual Investment for Dementia Research in Ireland (2010)<sup>3</sup>.

International comparisons [40] would suggest that Ireland had the highest public per capita spend on 'brain research' in Europe and would suggested that 40% of this is dedicated to dementia research.

Using Delphi methods to estimate the expected gains of scientific advances, Comas-Herrera *et al* [41] assess the opinions of a panel of dementia experts. The panel were moderately optimistic about the potential impact of scientific advances but the chances of Alzheimer's disease disappearing in the next 50 years were minimal. Projected expenditure (based on panel opinions) on long-term care would increase somewhere in the range of 36% to 60% by 2031. This is expected to fall short of the required increase in service level of 65% which in itself is based on the modest assumption that there would be no change in incidence rate or cost of care or institutionalization rates. Overall, this research at best indicates to a small reduction in the prevalence of dementia in the next 50 years.

<sup>3</sup> I would like to acknowledge with appreciation the assistance provided by the Health Research Board and the Higher Education Authority in attributing Irish level of investments in dementia related research.

While concerted effort to find a cure may lead to breakthroughs (e.g. from biomarkers or through drug combinations), policy planners would be advised to work on the assumption that the discovery of dementia cure is not imminent. Initiatives (such as national dementia strategy) which focus on patient centred care, collection of longitudinal data, offsetting residential care and providing optimal carer intervention should represent significant steps forward in the management of dementia.

## Conclusions and Recommendations

Dementia presents significant economic challenges for health care systems as well as impacting on families, social structures and medical thinking. Ireland places significant burden on the family in dementia care. Such burden can be better managed through appropriate services and interventions. International evidence indicates that carer support is central to achieving cost effectiveness in dementia care. Community based services are cost effective by reducing role overload, depression and the ultimate risk of long term care. Dementia care policy in Ireland should move towards a sustainable care infrastructure with explicit consideration of carer burden and optimal case management through payment by results.

### Recommendations

**1 Budget allocation** should explicitly consider the associated burden placed on informal carers. Investment in dementia-specific community support should address the imbalance of the burden of care and the over reliance on informal care. Insufficient funding is ultimately resulting in carer burnout and greater demand for long term care.

2 Ireland requires a **National Dementia Strategy** containing a detailed implementation plan, clear lines of accountability and which maintains links with other policy initiatives. Medium term objectives should address the significant demographic challenge that lies ahead in relation to dementia.

**3 Further research** is required to ensure service delivery systems are efficient and cost effective. Up-to-date measures of prevalence of dementias and a minimum dataset are needed and these should be combined with a service mapping to optimise present and future planning.

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