



An Economic Perspective of Dementia Care in Ireland¹

Executive Summary

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Policy Paper 1

"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). Despite its large potential impact, dementia continues to receive inadequate attention and is a relatively new area of policy focus. The World Health Organisation (WHO) observes a growing gap between budget allocation and the associated burden of mental health disorders, particularly in higher income countries. The economic burden of dementia ranks higher than stroke, heart disease and cancer combined. However, health care allocations for dementia continue to be substantially lower than each of these individual disease groups.

In terms of percentage of GDP, Ireland spends approximately half the OECD average. UK, Canada and Australia where dementia specific strategies have been implemented show sizable differences. See Figure 1.

Ireland is predicted to have the largest growth in the older population of all European countries in the coming decades. 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 indicates that the key priority for dementia is targeted interventions towards the carer.

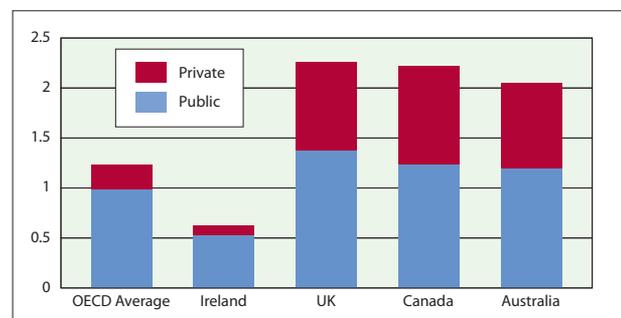


Figure 1: OECD, 2007

¹ The full version of the paper is available to download from www.alzheimer.ie or www.healthconomics.ie

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

Dementia Care in Ireland

Spending on dementia must be prioritised in a manner which will maximise benefits to society whilst maintaining optimal cost efficiency. The carer plays a critical role in dementia and is the focus of much debate.

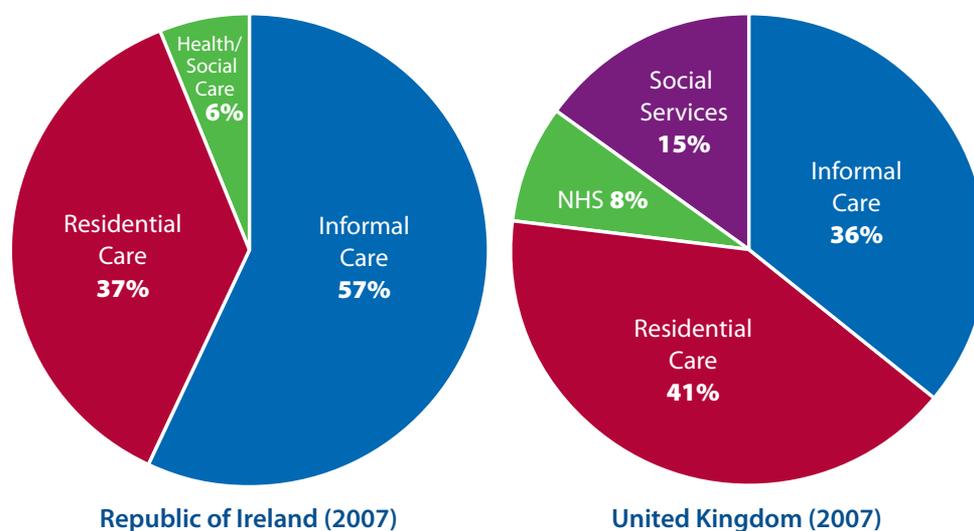


Figure 2: Distribution of care related costs by country (Ireland: O'Shea, 2007; United Kingdom: Knapp *et al*, *Dementia UK*, 2007)

Figure 2 highlights Ireland's greater reliance on informal (family) care than in the United Kingdom. With the presence of health and social care services at 23% in the UK there is a substantially less economic burden placed on families. O'Shea estimates the value of informal care in Ireland 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 (Knapp, Prince *et al*, 2007) 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 significantly increases on the informal carer. See Figure 3.

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. (see Trepel *et al* for full calculation).

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.

This level of carer burden is avoidable through appropriate support services and interventions. Current evidence suggests that the first line should be in assisting and supporting the carer to cope in their role.

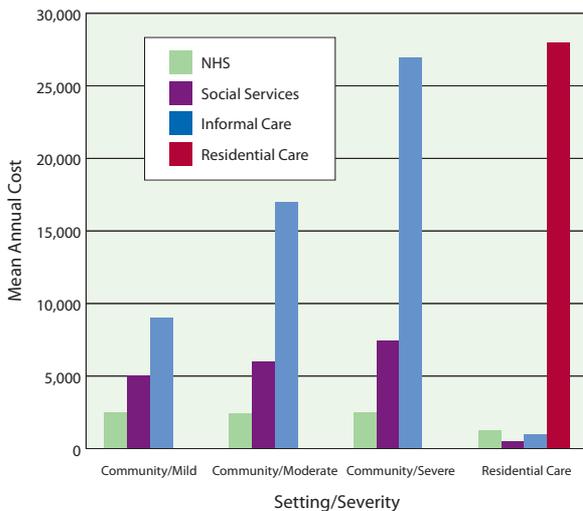


Figure 3: Annual costs of care by setting and severity (Knapp et al, Dementia UK, 2007)

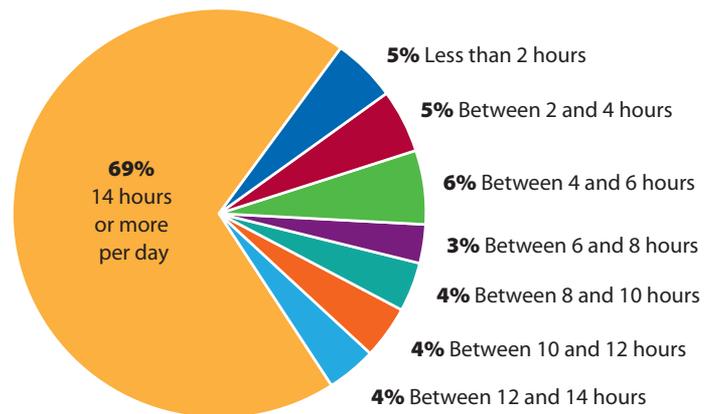


Figure 4: Hours of care in middle to late stages of dementia

The critical carer

Caring for a family member or relative has been referred to as the 'hidden patient' 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 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 interventions directed to the carer are critical and essential.**

Care for your carers

Cost-effectiveness research of carer directed interventions indicate 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, the study concludes that dementia caregivers who use these services consistently and for longer periods of time, maximise effectiveness.

Optimal gains are produced by encouraging early utilisation of services during the caregiving career to increase the range of benefits. Another significant study conducted an economic evaluation of community support initiatives that provided day and respite care. They found that despite additional costs of the service, day care was cost-effective in part by observed savings accrued in reduced long-term beds utilisation.

Systematic evidence collected on the effectiveness of interventions for carers of people with dementia, reviewed 127 studies (containing approximately 5,930 participants). Interventions included training for carer, informal support groups, planned, temporary relief for caregivers (inclusive of daycare, in-home and respite), cognitive behavioural therapy and counselling.

This meta-analysis finds carer interventions have a statistically significantly reduced burden, improved levels of depression and an increase in subject well-being, knowledge and ability. Also statistically significant improvements in symptoms of the care recipient are found. Combinations of interventions were associated with a reduced risk of the person with dementia's institutionalisation, particularly where 'lasting changes in the lives of the caregivers' were made. *(continued overleaf)*

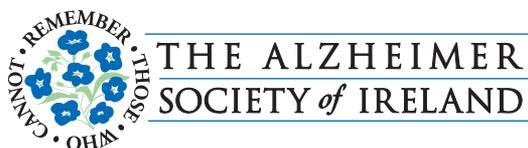
Conclusions and recommendations

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 carer 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 be to 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 supports 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 use of long term care.
- 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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