

An Economic Analysis of Home Care Services for People with Dementia

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Introduction

The economic impact of dementia has been estimated to equate to 1.09% of global GDP (PRINCE ET AL, 2015), remaining one of the foremost health and economic challenges facing society today. Globally, the cost is estimated at \$818bn per year (PRINCE ET AL, 2015). As a result a strategic approach to dementia care is becoming central to Government policy. In Ireland, dementia costs just over €1.69 billion per annum, with 48% attributable to costs of care provided by family and friends (CAHILL ET AL, 2012).

Consecutive Government policies have stated that a national priority is to support people to age at home (*Care for the Aged Report, 1968; Years Ahead Report, 1988; National Positive Ageing Strategy, 2013*). Broader health policy (*Future Health; A Strategic Framework for Reform of the Health Service 2012–2015*) also outlines a commitment to care for more people in their homes for as long as possible.

Specific to dementia, the *Irish National Dementia Strategy* (DOH, 2014: 15) states that the Health Service Executive (HSE) will consider how best to configure resources currently invested in home care packages and respite care

as to facilitate people with dementia to continue living in their own homes and communities for as long as possible and to improve the supports available for carers.

In recognition that an economic analysis of home care services for people with dementia is a useful tool to guide policy The Alzheimer Society of Ireland (ASI) commissioned an expert policy paper in 2015. This paper titled *An Economic Analysis of Home Care Services for People with Dementia*, was independently prepared by Dominic Trépel (PhD), Health Economist with the University of York.

This executive summary will provide an overview of this expert policy paper. It presents Trépel's expert analysis of home care for people with dementia in the context of currently identified needs in Ireland, focusing on who provides home care, what care is provided and when. It also provides recommendations on how home care services can be best configured to ensure an optimal arrangement of care for people with dementia.

When is Care Required for People Living with Dementia?

Dementia is a syndrome – usually of a chronic or progressive nature – in which there is deterioration in cognitive function (i.e. the ability to process thought) beyond what might be expected from normal ageing (WORLD HEALTH ORGANISATION, 2015). The impairment in cognitive function is commonly accompanied, and occasionally preceded, by changes in emotional and/or social behaviour, or motivation.

Activities of Daily Living (ADL) are 'daily self-care activities within an individual's place of residence' (KRAPP, 2002) and can be quantifiably shown to deteriorate as dementia progresses thus increasing demand for care (TRÉPEL, 2011). Wübker et al. (2014) term deterioration as a loss of 'ADL independence' and, for people with dementia (at risk of institutionalisation), losing independence is correlated with the highest change in demand for home care (HALLBERG ET AL. 2013; HALLBERG ET AL. 2014). O'Shea and colleagues (2007) suggest that the level of individual disability associated with dementia creates a need for personal care, social support and domestic assistance.

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

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Being able to live at home is very important to people with dementia (ALZHEIMER'S SOCIETY, 2012). There are a number of issues to consider when attempting to meet this preferred choice, as well as addressing the increasing prevalence of dementia that accompanies population ageing. For instance, Zabalegui et al. (2014) state that research on best practice interventions to support the care of people with dementia living at home cover a variety of interventions. Comparison of practice effectiveness is therefore difficult. This indicates that any policy decisions will have associated uncertainties in the deployment and outcome of home care.

In addition, the variety of potential agents contributing to dementia care, which is compounded by continuously changing demands and variations in the availability of family and/or formal carers, increases the likelihood of inefficient and inequitable arrangements of care. The goal for people with dementia and for wider society is therefore to provide an optimal arrangement of care. That is, maximising overall welfare with improved deployment of scarce available resources.

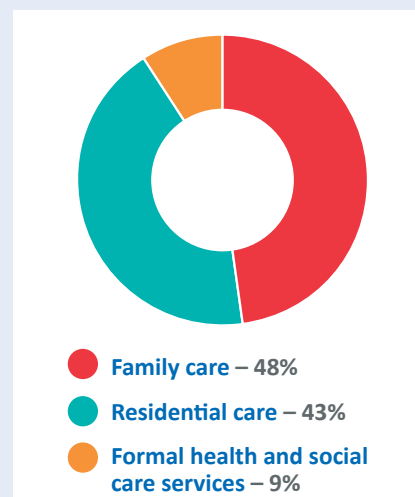
Who Cares for People with Dementia?

In Ireland there are an estimated 48,000 people currently living with dementia (PIERCE ET AL., 2014). Across this population not everyone will require high levels of care. It is however a progressive condition with a person's health and social care needs changing over time. As a result, each individual's circumstances and experiences are different and the provision of home care in each case will vary. Formal care is most often provided by public, voluntary and health and social care professionals (GANNON & DAVIN, 2010), although households may also enlist formal care through private channels.

FIGURE 1: ESTIMATING THE COST OF INFORMAL CARE

To quantify the economic impact of care provided by family members, UK estimates suggest public expenditure saves £8 billion a year in public expenditure (LILFFE, ROBINSON, ET AL. 2014). In Ireland, each year family care is estimated to cost €807 million (CAHILL ET AL, 2012). Figure one illustrates the breakdown of the cost of care.

Source: CAHILL ET AL, 2012



In community settings, care relies on the contributions of family or friends (CONNOLLY ET AL. 2014). Such care is most often unpaid and tends to be from individuals living in close proximity to the care recipient (BONSANG 2009). In Ireland, higher levels of care need is associated with increasing levels of family care and formal services were not found to respond where demand for care increases (GILLESPIE ET AL. 2014). However, research finds that formal provisions are often required to augment care and in this instance any provision must be cost effective (QUENTIN ET AL. 2010). Economic analysis suggests that arrangement of dementia care may lack coordination given an absence of a structured care plan underpinned by appropriate information systems (TRÉPEL, 2015).

Burdensome aspects of care therefore presents a significant and immediate threat to the balance of care for people with dementia (TRÉPEL, 2012A). Funding for home care supports aiming to address the overreliance on family members requires a consensus on *what we mean by home care services*. Such a consensus should specify the parameters to be placed on the current reliance on family care, and identify the proposed criteria for formal services

to ensure good quality, effective, and cost-effective dementia care at home (JONES, 2014).

What Type of Home Care is Currently Provided?

Home care is the generic term generally used to cover a range of care and support interventions delivered to a person, including older people, in their own homes. It includes support with domestic tasks, shopping, home maintenance, personal care, social activities, rehabilitation and recovery. Home care services also include self-care activities that a person must perform every day such as bathing, dressing, eating, getting in and out of bed, moving around, using the toilet etc. Its purpose and function varies greatly from place to place and service to service. Besides care provided by family members a number of other agents provide home care. They include the HSE, voluntary organisations, and private companies. In Ireland the State-funded Home Help Service and Home Care Support Schemes, collectively known as Home Care Packages (HCP), are two interventions developed to assist older people, including those with dementia, to

remain in their own homes for as long as possible.

In the operations of providing formal care, the HSE uses an Activities of Daily Living (ADL) approach, identifying ADLs as washing, taking a shower, assistance with changing position, oral hygiene, or help at mealtime, and assistance with essential domestic duties (like lighting a fire or bringing in fuel if there is no alternative heating source, or basic essential cleaning of the person's personal space).

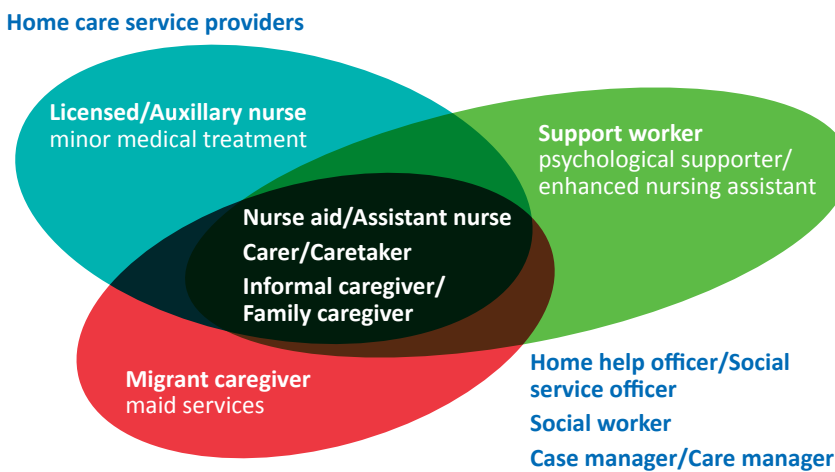
How is Care Best Provided in the Home?

Whilst research suggests that substantial benefits exist by remaining in one's own homes (versus long-term institutional settings), community care is often insufficiently resourced, less structured and may require focused effort to organise. There is a challenge presented in the provision of home care services to develop frameworks to co-ordinate and ensure that all available carers (formal or family) are visible and accounted for.

Lines of accountability underpinned by SMART objectives⁴, with the ultimate goal of maximising societal welfare, require an enhanced model of home care. An enhanced model requires the ability to adapt the intensity of care (as required by varying stages of dementia), routine assessment, with coordination and monitoring level integrated to ensure provider performance.

Given low rates of diagnosis, and an absence of community-based dementia care pathways, the majority of people with dementia living in the community are at risk of having a suboptimal care plan. The outcome of such a situation is that responses to the changing demands for care may be ad hoc and may be provided by a variety of individuals.

FIGURE 2: **INDIVIDUAL PROVIDERS OF HOMECARE**



Source: HALLBERG ET AL. 2014: P.6

There are multiple agents involved in the provision of home care. Figure 2 above summarises a European mapping system describing the range of agents involved in the provision of home care throughout the trajectory of dementia (HALBERG ET AL, 2014)

The variety of potential providers contributing to dementia care, compounded by continuously changing demands and variations in competencies of carers increases the likelihood of inefficient arrangements of care.

Based on available evidence the most effective way to provide care at home is taking a number of approaches including:

Organising care through a case management approach:

A recently completed Cochrane review determined current knowledge on the effectiveness of case management approaches to home support for people with dementia (REILLY ET AL. 2015). The review identified relevant research (all with very similar design) and analysis of this evidence suggests that case management reduces likelihood of institutionalisation by 18% at 6-month

follow-up. The research also interestingly finds evidence to suggest that case management may have a small but significant effect on improving symptoms of depression in caregivers.

Monitoring whether required care is being provided:

Recent research funded by the National Institute for Health Research U.K.† (NIHR) explores the feasibility (and effectiveness) of collaborative care for people with memory problems in primary care (LILFFE, WAUGH, ET AL. 2014). Using case managers, collaborative care aims for a structured management plan which systematically schedules patient follow-ups and plans enhanced communication and supervision.

Making use of valuable information being produced:

The CASPER study (OVEREND ET AL. 2014) used a case management collaborative care approach underpinned by appropriate information systems. In this model of collaborative care, an academically developed information system was used to monitor the delivery of a well-organised package of care and to implement evidence-based practice.

⁴Specific, Measureable, Attainable, Relevant and Time-framed (TRÉPEL 2012B).



Considering the Economics of Home Care Services for People with Dementia

People want to remain at home for as long as possible so there is a moral argument to consider how best to support this wish. There is also an economic argument, as sustaining people with dementia at home makes rational economic sense. For example, European analysis of average costs in dementia care deduced that *institutional long-term care* costs €4,491 per month compared to €2,491 for aggregate costs from *home care*; in relative terms suggesting a 1.8 (min-max: 1.4 – 2.4*) difference across all countries (WÜBKER ET AL. 2014).

The person with dementia may benefit from remaining at home but to solely focus on maximising utility gained by this person would overlook total societal welfare⁵. From a health economics perspective, society's primary objective should be to maximise overall societal welfare and it is imperative for policy to explicitly consider optimal arrangements for limited societal resources. For example, the impact of competing priorities for family carers exerts forces to limit available care, dependent on employment status and where the person lives.

Consider also that all agents involved in care, be it care provided by families

or formal providers, have competing priorities (e.g. healthcare or social care), and assume that efforts applied to competing priorities creates an alternative cardinal utility⁶. There is a need therefore to consider the dynamic relationship between providing care for the person with dementia with balancing competing priorities elsewhere in society.

This type of analysis, which applies notions of uncertainty⁷ and the value of information in dementia home care services raises key questions about: who is best placed to organise the supply of care; how best to monitor whether required care is being provided; and how this valuable information is captured and shared. These questions are addressed when we look at how care is best provided in the home.

RECOMMENDATIONS: Co-ordination, Collaboration and Information

The paper has built the argument that case management, collaborative care and information systems are important factors to improve overall welfare by addressing sources of inefficiency (i.e. information on deploying services). There is strong evidence to support this.

KEY RECOMMENDATIONS:

1. Adequate resourcing of home based care is required to meet the preferences of people with dementia to remain living in their own homes and to maximise overall societal welfare.
2. With a range of agents providing home care, a consensus definition on what is meant by home care services is required.
3. Better collaboration and coordination of the provision of care is required to address current inefficient arrangements of care provided through a case management approach.
4. Research is required to better understand which agents should provide what care, which specific interventions should be recommended and to translate policy recommendations into clearly visible changes in practice.
5. An enhanced model of home care requires the ability to adapt the intensity of care based on routine assessment that is coordinated and monitored using good information systems.




⁵This includes wider consideration of gains for society as a whole, including carers, healthcare professionals etc. beyond just the person with dementia.

⁶Cardinal utility is a view of utility measurement based on the presumption that the satisfaction of wants and needs is a quantifiable characteristic of human activity.

⁷Uncertainty relates to decision theory where decisions to allocate scarce resource must be made with imperfect information.

* Full References are available on www.alzheimer.ie

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