

## **Introduction**

The incidence of dementia is rising around the globe with increasing life expectancies. While some estimates suggest an upward trend from 36 million in 2010 to well over 100 million by the year 2050 (Hoey, 2012; Mihailidis, 2012), Alzheimer's Disease International (ADI) goes further in predicting 135.5 million people with dementia in 2050 (ADI, 2013).

The financial costs of dementia are extremely high. The overall estimated cost of dementia in 2010 was USD604 billion or 1% of the world's GDP, approximately 70% of which was accrued in Western Europe and North America where population ageing has matured. This sum is attributable to direct medical and social care provided by medically-trained professionals and professional caregivers, known as 'formal care', and unpaid care provided by family and others, known as 'informal care' (ADI, 2013). Dementia is one of the most expensive health conditions for society as a whole.

"If dementia care were a country, it would be the world's 18th largest economy, ranking between Turkey and Indonesia. If dementia care were a company, it would be the world's largest by annual revenue exceeding Wal-Mart (US\$414 billion) and Exxon Mobil (US\$311 billion)." [ADI, 2015]

Dementia is caused by gradual changes and damage in the brain, as brain cells degenerate and die more quickly than they would in the normal ageing process. The changes usually happen because of a build-up of abnormal proteins in the brain, and these abnormal proteins are different in each type of dementia. Alzheimer's Disease is the most common form of dementia, accounting for 60% to 80% of cases, in which the loss of brain cells leads to the brain shrinking. The cerebral cortex is particularly affected by this shrinkage, and symptoms reflect the fact that this area of the brain is responsible for processing thoughts and many complex mental functions, such as storing and retrieving memories, calculation, spelling, planning and organising.

Vascular dementia accounts for approximately 10% of cases in itself, but is also found as a mixed dementia with Alzheimer's. In the vascular form of the disease the brain's blood supply is interrupted, most commonly through atherosclerosis caused by chronic conditions such as high blood pressure, Type 1 diabetes or smoking, or an acute interruption to blood supply to the brain as occurs during a stroke.

Less common forms of the disease include dementia with Lewy bodies (small, circular lumps of protein that develop inside brain cells) which is closely related to Parkinson's Disease and can manifest with similar symptoms, Creutzfeldt-Jakob Disease, and fronto-temporal dementia (Alzheimer's Association, 2015).

As an irreversible neurodegenerative condition, dementia is a leading cause of disability for older people (Perilli, 2012). The progressive decline in cognitive and physical function causes loss of memory, problems with communication, judgment and decision-making, disturbances in motor function, behavioural changes, and emotional effects such as depression, apathy and social withdrawal (Boger, 2005; Cohen-Mansfield, 2013; Mihailidis,

2012; Perilli, 2012; Serdà i Ferrer, 2014). Despite the progressive decline in functioning, people can live for as long as 20 years with dementia (Heyn, 2004). The disease is categorised by the health sector into the three stages of mild, moderate and severe, although these stages can overlap and the stage boundaries are often blurred (Mihailidis, 2012). Mild dementia is classified according to subjective complaints of memory deficit and cognitive performance but no objective evidence of these at clinical assessment. The moderate stage is assessed according to clear-cut evidence of deficit such as decreased memory for personal history and current and recent events, inability to handle finances or travel, and inability to perform complex tasks. Severe dementia is classified on the basis of the individual's inability to survive without assistance, their disorientation, severe memory deficit, incontinence in some cases, and personality and emotional changes (Reisberg, 1982).

It is commonly believed that older people with dementia tend to live in residential care facilities, but in fact between 60% and 70% live in the community in developed countries, reflecting the personal wishes of the majority to live at home and maintain a normal lifestyle for as long as they can (Elliott, 2010; Low, 2015; Mihailidis, 2008).

### **Reablement for people with dementia**

Dementia should be considered an independent factor for the reablement approach, so that people with dementia may have the opportunity to benefit from rehabilitation and reablement whether or not they are referred to a reablement service as a result of illness or injury. Reablement introduces non-pharmacological strategies to help the older person with dementia to cope with the disease and continue to engage in everyday activities for as long as possible. Reablement interventions typically complement pharmacological treatments, such as acetylcholinesterase inhibitors, to improve or delay the progression of memory loss and incapacity in carrying out the activities of daily living (ADL).

Reablement planning is person-centred and occurs in consultation with the individual and their caregiver, focusing on their strengths, employing their preserved capabilities to protect and maintain quality of life irrespective of their level of cognitive status (Gitlin, 2010). Strategies target improvements in performance and independence to a degree of functionality that is acceptable to the person with dementia and their caregiver, as well as maintaining health (prevention of pain or discomfort), safety and dignity, and creating the potential for enjoyment and happiness through recreation and social connectivity (Cohen-Mansfield, 2013; Francis, 2011; Gitlin, 2010; HammondCare, 2014; Olazarán, 2010). Interventions at the different stages of dementia are predicated on assessment of actual need and wishes to allow for individualised, person-centred care (Mountain, 2005). When dementia reaches the severe stage, the reablement focus shifts to providing an environment that is safe and protective of the person's quality of life and sense of personhood. Emotional processing can continue throughout the disease process and therefore therapeutic interventions to decrease sadness and pain, to increase pleasure and happiness, and to make the person feel loved and cared-for are indicated for the whole lifespan (Mihailidis, 2012; Olazarán, 2010).

The core focus of reablement interventions for people with dementia is the dyad of care recipient and caregiver. The increasingly high dependency and complex needs of the person

with dementia impact strongly on the health and lifestyle of the caregiver. Some caregivers find their role uplifting and highly meaningful, and some people with dementia experience a satisfying degree of pleasure and contentment (Cohen-Mansfield, 2013). However, a diagnosis of dementia often represents entry into a world of suffering. The perceived stigma attached to loss of memory and behavioural unpredictability can cause the person to react with intense anxiety, retreating from social engagement and becoming depressed, fearful and apathetic even while their pathophysiology is mild (Clare, 2013). For the caregiver, the combination of responsibility for the physical health and safety of the care recipient and protection of their emotional needs has come to be known as the 'caregiver burden'. It is associated with high stress levels and decreased health and well-being for the caregiver, especially as the disease progresses (Elliott, 2010). Younger caregivers may face loss of employment income as well as isolation from their social group. Older caregivers, often the spouse or sibling of the person with dementia, may themselves have poor physical health and a degree of frailty (Mihailidis, 2012). Financial stress commonly affects both caregiver groups (Cohen-Mansfield, 2013).

### **Evaluating the efficacy of reablement**

Before reviewing the evidence it needs to be noted that the relatively new reablement community health and social care model has yet to be researched in the context of people with dementia to the extent and depth required to unequivocally demonstrate its efficacy and cost-effectiveness. One causative factor is that older people with cognitive deficits are considered a particularly vulnerable population, and are often excluded from research trials on the grounds of difficulty with reliable data collection and ethics approval challenges (Fairhall, 2013; Heyn, 2004; SCIE, 2013). Consequently, many interventions have only been studied in the comparative short-term, using small sample sizes and without randomised controlled measures. Moreover, a lack of consensus exists for responsive outcome measures in clinical trials, such that reviewers of psychosocial interventions throughout Europe identified 22 outcome measurement instruments which could potentially be used to reflect specific and generic measures (Moniz-Cook, 2008). Similarly, outcome measurement for assistive technologies is relatively new as many projects are still prototypes and very few have been tested in the 'real world' or been the subject of longitudinal studies (Mihailidis, 2012). Therefore, the following discussion of necessity rests on statistically significant results and 'high probability' outcome indicators.

It is now understood that lifestyle—that is, leisure pursuits, social engagement, education and occupation—can provide a 'cognitive reserve' that enables the individual to cope better with the neuropathy of dementia. Cognitive training can usefully exploit this reserve potential in the context of reablement, in that individuals with new learning impairment may be able to access their procedural memories, especially in the earlier stages of dementia (Liberati, 2012). This enables therapeutic interventions to prolong the capacity for undertaking activities of daily living (ADL) and leisure pursuits which rely on previously encountered skills, routines, activities and communication. Evidence also suggests that some new verbal and behavioural learning may be possible in early-stage sufferers, with the provision of extra support to accomplish tasks (Clare, 2013; Gitlin, 2010).

Some cognitive training strategies target specific skills such as language, attention, memory and executive functioning, while others focus on the general improvement of cognition (Cognitive Decline Partnership Centre, 2015; Liberati, 2012; Thivierge, 2014). Statistically significant positive results have been noted for particular measures of cognition as well as improved achievement of individual goals (Bahar-Fuchs, 2013; Clare, 2011; Thom, 2011;). However, findings are still inconclusive for cognitive ability enhancement through regular physical exercise, and for sustainability of cognitive improvements (Heyn, 2004; Serdà i Ferrer, 2014; Teri, 2012).

Opinion is divided on the evidence for gains from cognitive training in personal and social activity. While some assert that outcomes are inconclusive (Clare, 2010, 2013; Martin, 2011), others find positive indicators in research on psychosocial interventions to reduce high-risk factors for institutionalisation such as depression, behavioural volatility, and the caregiver burden. For example, interventions targeting caregivers through psychosocial skills-training and support in managing behaviours, improving communication and enhancing enjoyment for the care recipient are showing successful potential, as are shared physical exercise programs for both care recipient and caregiver (Teri, 2012).

Cognitive training is just one example of a category of reablement interventions known as 'non-pharmacological interventions' (NPIs). Other NPIs include: strategies for maintaining social connectivity; environmental re-design to promote independent functioning and safety; therapeutic use of art, music and touch for recreation; assistive technologies such as cueing devices like memory boards for undertaking activities of daily living (ADL) and for orientation; and educational and emotional support for the caregiver (Gitlin, 2010; Teri, 2012).

Non-pharmacological interventions (NPIs) have several clear advantages. They are practical, adaptable to the individual to a large degree, often inexpensive, and without side effects in contrast to most medicines. They are often considered as complementary therapy to medical treatment. For example, while psychotropics can effectively manage certain behaviours like paranoia, mood disorders and hallucinations in many patients, they have not shown the same level of success for the symptoms of restlessness and wandering, agitation and repeated verbalisation (Gitlin, 2010). In contrast, NPIs can usefully be employed to manage behavioural symptoms and to enable ADL to be accomplished (Olazarán, 2010). In light of the evidence some American peak bodies, such as the American Association for Geriatric Psychiatry and the American Society of Neuropsychopharmacology, are recommending that NPIs be the first treatment of choice for people diagnosed with dementia (Gitlin, 2010).

The vulnerability of the older population with dementia is typified by the safety risks they encounter, often on a daily basis. Older people with dementia have a five-fold risk of falling compared to those without the disease (Boger, 2011). The positive outcome indicators of physical exercise programs include improved mobility and suppleness which can reduce the risk of falling, better general health and behavioural management, and improved quality of life (Heyn, 2004; Serdà i Ferrer, 2014). Other safety risks include wandering away from home, injury from sharp objects, and slow response to an emergency situation in the home. Safety measures—such as an 'easy-reach' or computerised detection system for falls or active gas burners, and customisable alarms that sound when the person with dementia

exits the home or gets out of bed at night—are demonstrating value in protecting the person with dementia from harm and alleviating anxiety in caregivers (Mihailidis, 2012; Wey, 2005).

The world of the ‘intelligent devices’ or Assistive Technology (AT) shows increasing promise in reablement interventions for people with dementia and their caregivers at home, both in activities of daily living (ADL) and recreational pursuits. Using computer-based intelligence, some devices prompt the person with dementia to complete an ADL they have forgotten how to do, such as handwashing, while others orientate them to their physical environment. Healthcare providers can connect with their patients in the community through audio-visual systems which store and share information and data, enabling treatment advice to be administered in the virtual space (Hoey, 2012).

Assistive Technologies are also being trialled in devices to enable or support communication, socialisation and leisure activities. Aside from the important quality of life benefits of mental stimulation, increased happiness and emotional satisfaction, evidence suggests that creative activities can reduce the risk of dementia and slow cognitive decline (Mihailidis, 2010, 2012). The impressive range of assistive technologies in the field of leisure and creative expression facilitation includes art, music, cooking and digital video games, among others. Two such examples are computer-based projects using touch screen technology to create customised digital games that the person with dementia can play independently, and a multimedia database of songs, photographs, video clips and music for individuals with dementia and their caregiver to explore together, thereby tapping into preserved memories which promote enjoyable reminiscences (Astell, 2013, 2014; Boger, 2011; Clare, 2013; Lancioni, 2013; Leuty, 2013; Liberati, 2012; Mihailidis, 2010, 2012; Yamaguchi, 2012).

Reablement activities are often facilitated by care staff in the person’s own home—such as art therapy, which may be supported by home visits from the therapist or remotely using an assistive technology system. Activities may also take place in a day care centre. One study in Belgium concluded that this setting is well suited to people with mild to moderate dementia. It facilitates the exploration of ADL performance with strategies to optimise completion of the task. In addition, spontaneous socialising can occur through involvement in various activities alongside other people in a natural setting. The time spent in day care also provides caregiver respite and support (Adam, 2000; Liberati, 2012).

There is strong evidence that interventions for caregivers improve their health and well-being through strategies such as in-home exercise programs, skills-training in managing behavioural symptoms, and dementia education (Maslow, 2012; Menne, 2014). In a longitudinal study of the health of caregivers in the USA, caregivers reported improved sleep patterns, higher self-rated physical and emotional health, a decreased sense of burden, and alleviation of depression (Elliott, 2010). There is also evidence to show that multi-component non-pharmacological interventions founded on education and support for the caregiver can delay transfer of the person with dementia to long-term residential care (Gitlin, 2010).

Reviewers conclude that a departure from the previous ‘silos research and training approach’ in favour of collaboration is essential in order to find solutions to the complexities of ageing in today’s world. This is exemplified in the inter-professional healthcare team, which is well

suited to complex conditions like dementia. A flexible approach is required, adjusting strategies to accommodate often unpredictable changes to cognitive function, behaviour and mood (Winstein, 2012). Good collaboration and communication between medical and allied healthcare providers enable flexible problem-solving, co-ordination and delivery of care to the person with dementia and their caregiver (Gitlin, 2010). Outcomes are shown to further improve when the primary caregiver is included as an equal member of the team, and can delay transfer of the person with dementia to residential care (Clare, 2010; Liberati, 2012; Maslow, 2012).

### **Is reablement cost-effective?**

Insufficient research is prohibiting conclusive evidence on the cost-effectiveness and efficacy of reablement for people with dementia (Mountain, 2005; Olazarán, 2010). There is indirect evidence to support real cost savings in home care, although expenses increase as the disease progresses and more support is required. When the hidden costs of informal care (including loss of earnings for the primary caregiver) are taken into account, home care may not offer cost savings in comparison with residential care (Bowes, 2013; Low, 2015). There is also little evidence at present to suggest that reablement reduces medical and allied healthcare costs. However, compensatory benefits exist in quality of life improvement measures, indicating statistically significant value both for the person with dementia and for the caregiver's health and well-being (Clare, 2010; Liberati, 2012).

The cost-effectiveness of assistive technologies (ATs) as enablers of function is as yet undetermined, although indirect indications of cost savings are found (Bowes, 2013). Spanning a wide spectrum from commercially available and relatively simple technological tools for memory prompting and orientation to artificially intelligent wheelchairs, many ATs are regarded as having potential benefit but are considered too expensive for most families. A cost evaluation is not yet available for a number of devices that are still undergoing trials as prototypes. AT investigators suggest that costs will decrease over time as technology becomes more widely accepted and employed in home care, and that some ATs may become available through medical insurance in the future (Boger, 2014).

### **Barriers to successful reablement**

Factors impacting on the success of reablement among people with dementia include a lack of education about the disease, staff training challenges, the lack of services and service models targeted to this population, ethics and privacy considerations, the public perception of dementia, and gaps and omissions in the research.

### ***Education about dementia:***

People suffering from dementia present a unique challenge as a result of their cognitive changes and memory deficits, compounded by behavioural symptoms and low mood states that inhibit motivation. While it is vital to involve caregivers in reablement strategies to optimise their potential for efficacy, this is not always possible or easy to achieve (Gitlin 2010).

Notwithstanding the impressive number of evidence-based non-pharmacological interventions and care practices that show success in helping at least some people live well with dementia, public awareness of these is extremely low (Maslow, 2012). This may partly be ascribed to the use of language that is not well understood or meaningful to people in the community. Terms such as ‘intervention’ and ‘non-pharmacological’, for example, may be confusing or even have negative connotations. In addition, the absence of an accepted standard classification system may inhibit a clearer understanding of interventions and care practices. Such a system would reveal the characteristics of those people likely to benefit from each intervention and the nature of the problems each one has been shown to reduce or resolve (Maslow, 2012).

A two-year project in the United Kingdom on self-directed care and support for people with dementia and their caregivers found that real choice and control were achieved by some individuals, although poor community understanding of what self-directed care is and what it can accomplish caused a persistently low uptake of this care scheme (Mental Health Foundation UK, 2011). Another self-directed care project in the United Kingdom included a component whereby participants controlled their own social care budget as an empowerment measure. Despite the challenges, with educational support positive outcomes were achieved for some participants (Moore, 2011).

### ***Staff training challenges:***

While many managers and front-line staff are embracing the reablement principles with enthusiasm (Francis, 2011), experienced home care staff in particular can be challenged by the paradigm shift from doing things ‘to’ or ‘for’ the person to motivating and encouraging them to become as functionally independent as they can be (Glendinning, 2010; Wilde, 2012). This is compounded by a common belief that people with dementia are less likely to benefit from reablement interventions than other older people because they are unlikely to move towards a significant degree of independence (Francis, 2011; Glendinning, 2010). In communities where the reablement model co-exists with the mainstream home care service evidence shows that staff can be confused by the two different sets of skills, which can lead to decreased staff and user morale (Miller, 2013).

### ***Ethics and privacy considerations:***

Assistive technologies in the home are showing promise for enhancing quality of life and decreasing costs of external care. However, violations of privacy could occur, particularly when computerised devices are monitored from elsewhere and may be located in private areas of the home such as the bathroom (Bowes, 2013). The ethical pathway to obtaining consent can be problematic if the person with dementia has significant cognitive disability and the caregiver has a poor grasp of technology (Mihailidis, 2012). Privacy dictates that users have a right to know and have a say in how personal data is stored and used, although this can be challenging to achieve in practice (Boger, 2014). Maintaining the ‘personhood’ of individuals with dementia is also significant, and AT as a tool may breach this fundamental right by crossing the line from doing *with* the individual to doing *for*. Examples include devices with orientation and monitoring intent such as tagging (Astell, 2006).

***Public perception of dementia:***

Researchers agree that it is time to challenge the common assumption that people with dementia cannot learn new skills and that any intervention is therefore bound to fail or even have an adverse impact (Mountain, 2005). A reframing of dementia is called for, based on an acknowledgement that assisting individuals to live well with dementia rather than succumb to the pervasively negative associations of the diagnosis can bring about considerable change (Clare, 2013). Any measures taken in consultation with the person with dementia and their caregiver to improve quality of life and maintain the person in the comfort and familiarity of their own home for as long as possible will be more effective if they occur against a backdrop of community understanding of what people living with dementia are capable of doing rather than what they are no longer capable of doing (Clare, 2013; Gitlin, 2010).

***Gaps and omissions in the research:***

Perceived gaps in the research include, but are in no way limited to: focusing on the cause of Alzheimer's Disease and other dementias to the detriment of research into assisting people to live well with dementia (Clare, 2013; Low, 2015); scant research into treatments and care practices for late-stage dementia sufferers, people under the age of 65 years with dementia, ethnic and racial minority groups, those who live alone with no informal care support, people with complex co-morbidities and dementia, and people with an intellectual disability who develop dementia. However, a number of important trials are currently underway, and these will contribute richly to the evidence base once analysed and published (Maslow, 2012).

*This paper was prepared by Ms Vyvyan Mishra with contributions from Associate Professor Chris Poulos*

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