

## Chapter 3

# Assistive Technologies and the Carers of People With Dementia: Empowerment and Connection

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### ABSTRACT

*Assistive technologies have a role in supporting both formal and informal carers of people with dementia, and in maintaining the independence, and quality of life of both people with dementia and their carers. The authors report a narrative review of the use of technological interventions to empower the carers of people with dementia, and relate this to a model of ageing well. They argue that this highlights the importance of empowering and connecting with carers in order to increase their participation and connection in the care of their relative/client; and conclude that both empowerment and connection contribute to maintaining autonomy and well-being of both carers and people with dementia. Technological interventions should not be used as alternatives to connection. The emphasis in practice should be on empowering and connecting with both carers and people with dementia.*

### INTRODUCTION

In the United Kingdom (UK) currently, there are about 800,000 people with dementia, of whom approximately 665,000 live in England. Dementia costs the UK economy £17 billion a year, and, in the next 30 years, the number of people with dementia in the UK will double to 1.4 million, with care costs trebling to over £50 billion per year (Alzheimer's Society, 2007). The care of people with dementia presents a huge challenge to society now, and demand is set to increase further in the future.

There are approximately six million carers in the UK: 1.4 million of them provide unpaid care for more than 50 hours per week (Office for National Statistics, n/d; The NHS Information Centre Social Care Team, 2010). The work of unpaid carers makes a significant contribution to the UK economy, and

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it is estimated that carers save the taxpayer approximately £119 billion per year (Buckner & Yeandle, 2011), equivalent to £2.3 billion per week. The Alzheimer's Society estimates that there are 670,000 people in the UK acting as primary carers for people with dementia (Alzheimer's Society, 2012) and unpaid informal carers are a major part of the support system for people with dementia. Many of the carers of people with dementia are themselves elderly, and may have long-term health conditions or disability. Two-thirds of all people with dementia live in their own homes with unpaid carers providing most of their support. The EURO CARE study (Schneider, Murray, Banerjee, & Mann, 1999) found that half of all people with dementia in the community received at least 35 hours of informal care per week. Although many carers report personal satisfaction from their caring role, it is recognised that unpaid caring has a considerable impact on the carer's health and well-being and can lead to emotional and physical exhaustion, depression, poor general health and isolation (Alzheimer's Society, 2013a).

The impact of dementia on the families of those with the condition is profound. Dementia results in a progressive decline in multiple areas of function, including memory, communication, language and daily living skills (Department of Health, 2009). Moreover, people with dementia may develop behavioural and psychological symptoms (BPSD) such as depression, psychosis, aggression or wandering. BPSD are common, often problematic for carers, and may affect almost all people with dementia (Savva et al., 2009), complicating care at any stage of the illness.

## **Formal and Informal Carers of People with Dementia**

People with dementia are cared for both by formal and informal carers. Family carers of people with dementia may be old and frail themselves, with high levels of depression and physical illness, and a diminished quality of life (Alzheimer's Society, 2007). Carers of people with dementia also experience greater strain and distress than carers of older people with other long-term conditions (Moise, Schwarzing, Um, & the Dementia Experts' Group, 2004). Many carers of people with dementia, particularly those caring for someone in the later stages of the illness, feel ill-equipped to deal with agitated behaviours (Newbrunner, Chamberlain, Borthwick, Baxter, & Glendinning, 2013). BPSD not only causes significant distress in carers but is often the singular most important factor in the early institutionalisation of people with dementia. Hence, training and support for carers are regarded as potentially valuable: expert carers programmes offer a way of delivering training and peer support to enable carers to care for their loved ones for as long as possible.

Traditional ways of meeting the needs of people with dementia continue to involve institutionalisation. Approximately half a million people in Britain live in residential, or nursing homes looked after by care staff or formal carers and about four-fifths of those in care homes have dementia (Independent Commission on Whole Person Care, 2014). In addition, people with dementia living in the community frequently receive formal care provided by paid staff from health and social services providers in their own homes and during hospital admissions. This staff ranges from qualified professionals such as nurses to care staff with few or no formal qualifications. Due to challenges in communication and a lack of understanding of dementia, there is concern that formal care of people with dementia in all settings often fails to promote dignity and respect and may sometimes breach fundamental human rights (Alzheimer's Society, 2014; Tadd et al., 2011). Challenges remain in ensuring the formal care workforce is effectively prepared to provide dementia care, and MacDonald and Cooper (2007) predicted a crisis of availability of institutional care places for people with dementia, calling for investment in affordable good quality domiciliary care. The main function of long-stay care for old people is now to provide for

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