

**Final Report**  
**Beyond Respite: Designing Effective Wellness  
Programs for Carers**



**Dementia Collaborative Research Centre:  
Carers and Consumers**



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## **Disclaimer**

The views expressed in this work are the views of its author/s and not necessarily those of the Australian Government.

## EXECUTIVE SUMMARY

This study was conceived with the aim of adding to the body of knowledge on the wellness needs of carers, so that more effective interventions to support carers of people with dementia will be possible. It is well established in the academic literature that carer health and wellbeing is impacted by the caring role. Respite care, where the care recipient is placed in temporary care, is often cited as an opportunity for the carer to experience temporary relief from the role. However, there is mixed evidence for the effectiveness of respite for either reducing carer burden or affecting institutionalisation for the care recipient.

The project methodology had two stages. In the first stage a comprehensive review of the literature was conducted, examining the impact of caring using Hettler's six dimensions of wellness as a comprehensive model through which to examine the carers' lives; which type of interventions were most effective in supporting carers. In the second stage, qualitative in-depth interviews and focus groups were held with current and former carers and respite workers.

The literature review indicated that carers are impacted across all six of Hettler's wellness dimensions, and that effective interventions that aim to support carers in their role need to be multi-faceted.

The qualitative interviews with carers provided a comprehensive understanding of the profound impacts of being a carer in contemporary Australia. Carers identified how their role had impacted on their wellness dimensions, and identified gaps in the provision of resources and support services for carers.

The carers in the study identified a number of ways in which their wellness could be better supported. These include the following recommendations:

- Education for carers on dementia and the resources and support services they are eligible for;
- Education for carers on the need to maintain their own health and wellbeing and strategies for achieving this;
- Education for carers' families;
- Further education and training for health care professionals on recognising dementia to assist in earlier diagnosis and management;
- Education for General Practitioners on the need to recognise and support the health and wellbeing of carers.

# INVESTIGATORS

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## **PURPOSE AND AIMS**

The purpose is to describe and extend the existing knowledge base in relation to understanding wellness and its relationship to carers of people with dementia and to identify areas for further research.

The aims of this project are to:

1. Review relevant academic and grey literature in relation to the wellness needs and experiences of carers of people with dementia;
2. Identify how carers define and perceive wellness;
3. Identify how carers' wellness is impacted by their care responsibilities;
4. Gain an understanding of the supports/resources carers feel would maintain and improve their wellness;
5. Lay a foundation for future research and practice development for carers of people with dementia through exploration of the data from this study.

## BACKGROUND

This study originates from an understanding that carers of people with dementia can be impacted by the caring role. In 1969, Golodetz, et al described the challenges of being a carer for a person with a chronic illness in particularly stark terms. In the intervening years much research has been conducted with carers on the stresses that can be placed on their health and wellbeing arising from the caring role. Research also suggests that carers of people with dementia may have their health and wellbeing impacted more than carers of those with other conditions.

A considerable body of research has addressed the specific impacts of being a carer of a person with dementia (physical health, mental health, social disruption). However, there is an increasing recognition that health and wellbeing are not solely grounded in the bio-medical model. A more nuanced understanding of health has emerged in the years since the latter half of the 20<sup>th</sup> century. The WHO constitution recognised that

*Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity (WHO, 1948).*

Furthermore, more recent research has indicated that health and wellbeing can be influenced by a complex range of factors which are often beyond the control of the individual. (Hettler, 1976; WHO, 1986 [Ottawa Charter]; Larson, 1999; Myers & Sweeney, 2004; WHO, 2003 & 2008 [Commission for the Social Determinants of Health]; Raphael, 2008).

This study seeks to understand the multiple impacts on health and wellness arising from being a carer for a person with dementia and inform the development of interventions that can support carer wellbeing.



## METHODOLOGY

This project took the form of a narrative literature review and a qualitative study.

### *Narrative literature review*

In preparation for a qualitative component of the study seeking to explore the wellness needs of Australian carers, a narrative literature review was undertaken to identify existing knowledge in relation to wellness and carers of people with dementia. The review filtered the carer literature through Hettler's wellness dimensions - a model which emphasises six broad and inter-related aspects of overall health: *physical, intellectual, social, spiritual, emotional and vocational*.

The initial search strategy included the terms *dementia, wellness, wellbeing, carer\**, and *caregiver\**. (The term 'carer' is used to describe the role in Australia, but the international literature uses both carers and caregivers as a descriptor. For ease of use, they will be referred to as carers, wherever possible, within this report). Databases searched were CINAHL, MEDLINE, Cochrane Library and Web of Science. Grey literature was also included in the review. Literature was limited to English language. No date limits were set in the search. The search strategy was then extended to also include literature on published interventions aimed at improving the health and wellbeing of carers of people with dementia. This latter search returned 943 articles for the period 1995-2012, reflective of the desire on the part of policy makers and health professionals to develop more effective systems of support for this population.

In addition to individual research articles, the searches also returned a number of systematic reviews and meta-analyses.

### *Qualitative study: interviews and focus groups with carers and care workers*

The study envisaged recruiting 50 carers of people with dementia to understand their thoughts and experiences of 'wellness,' and to discuss their suggestions for supporting, maintaining and improving their wellness. In addition, the research team sought to recruit 20 care workers to provide some context and additional knowledge on the experiences of carers.

### *Ethics approval*

Ethics approval for this study was sought from, and approved by, the Medical and Community Human Research Ethics Advisory Panel at the University of New South Wales (Ref # 2012-7-11). After preliminary consultations with stakeholders about the challenges involved in recruiting carers, it was decided to seek an ethics amendment to accommodate the recruitment of former carers as participants; and to allow for carers to participate in one-to-one interviews. These amendments were approved by the HREA (letter 21.8.12). Refer to appendix 1.

# RESULTS

## *Literature review*

Despite advances in the understanding of the many factors that shape health, popular experience and perceptions of health remain shaped by the bio-medical model and the importance placed on the interaction between a doctor and 'patient' in response to an illness or feeling unwell. However, health cannot be solely defined by, or limited to, disease processes that arise in an individual. Those who advocate a more nuanced, preventative approach to health understand that a complex range of factors and influences shape health, with many of these factors determined by circumstances beyond the control of the individual. This broader approach had its origins in more positive definitions of health that emerged after World War Two, culminating in the 1948 preamble to the WHO constitution which stated that

*Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity (WHO, 1948).*

Halbert Dunn was one of the earliest proponents of what he termed 'high-level wellness' defined as

*An integrated method of functioning, which is oriented toward maximizing the potential of which the individual is capable (Dunn, 1959).*

Dunn's novel and more holistic approach to health has been reflected in the ongoing discourse about the meaning of health in recent decades (Hettler, 1976; WHO, 1986 [Ottawa Charter]; Larson, 1999; Myers & Sweeney, 2004; WHO, 2003 & 2008 [Commission for the Social Determinants of Health]; Raphael, 2008).

In 1976 Dr Bill Hettler released his 'six dimensions' of wellness, which were to form the philosophical base for the National Wellness Institute, which he established the following year (Hettler, 1976). His view was that optimal human health is a dynamic balance between the following health dimensions: *physical; intellectual; social; spiritual; emotional; and vocational.*

## *The importance of carer health and wellness*

In 2009 it was estimated that over 250,000 Australians had dementia, the majority of who were being cared for by spouses or family members (Australian Bureau of Statistics, 2009). Notwithstanding advances in the identification and management of risk factors for dementia at the population level, and the advent of medications to slow the rate of symptom progression in established cases, changing demographic trends and increasing life expectancy will mean that the number of people with dementia in Australia is expected to rise to nearly 1 million by mid-century. Most of these people will be cared for by family carers (Alzheimer's Australia, 2011; Xie et al., 2008).

In a particularly prescient 1969 paper, Golodetz, et al describe the lot of the carer:

*She is not trained for her job, a priori. She may have little choice about doing the job. She belongs to no union or guild, works no fixed maximum of hours. She lacks formal compensation, job advancement and even the possibility of being fired. She has no job mobility. In her work situation, she bears a heavy emotional load, but has no colleagues or supervisor or education to help her handle this. Her own life and its needs compete*

*constantly with her work requirements. She may be limited in her performance by her own ailments (Golodetz, et al, 1969, p390).*

Nearly half a century later, the lot of the carer is little different.

The value of informal caring provided by families of people with dementia in Australia is estimated to exceed AUD 5 billion *per annum* (Alzheimer's Australia / Access Economics, 2009). In some studies, it was estimated that caregiving equated to the equivalent of a half-time job (Mestheneos & Triantafillou, 2005). Informal caring allows people with dementia the opportunity to live at home for much longer than would otherwise be possible (Bruen & Howe, 2009). Moreover, informal caring affords care recipients a greater sense of independence (Sabat, 2009) and dignity than they would perhaps experience in residential care. Carers often express their commitment to the care recipient in terms of reciprocity for past care, an integral part of marital commitment, or even the realisation that they themselves might need such care in the future. Consequently, putting a care recipient into residential care is seen by many carers as the option of last resort (Peacock, et al, 2010).

However, caring for someone with a chronic illness such as dementia is complex and demanding and requires more than just providing assistance with daily living. The dyad relationship, between carer and care recipient, can become a dynamic that is characterised by almost constant care for, and often challenging behaviour from, the care recipient (De la Cuesta, 2005; George, et al, 1986; Draper, et al, 1995; O' Rourke, et al, 2003; Gusi, et al, 2009; Butcher, et al, 2001). For several decades, carers in general were described as 'hidden patients' (Fengler & Goodrich, 1979). While carers are all too aware of the demands that caring places upon them, studies have shown that carers [of loved ones with dementia] have a *High motivation to care [and a] high willingness to continue caregiving* (Dohner, 2006, p10).

Importantly, deterioration in carer health can result in a care recipient having to enter institutional care (Cahill & Shapiro, 1998; Chenoweth & Spencer, 1986; Bond & Clark, 2002). From a societal perspective, supporting carers of people with dementia would seem the most sensible policy to pursue for carers, care recipients and society.

There is a considerable body of literature that discusses the health impacts and experiences of caring for someone with dementia. These often come from distinct reference points or perspectives (physical health such as injuries, mental health such as depression, etc.). While these studies contribute much understanding to the lived experiences of those who care for someone with dementia, they do not always articulate the complex reality of being a carer. There are numerous ways in which a diverse range of complex factors (social, environmental, structural, economic, etc.) and lived experiences of carers impact on their health. These are often inter-related, dynamic and synergistic. George & Gwyther (1986), for example, analysed carers' well-being through their physical health, mental health, social participation and financial resources.

## *Caring and its impact on wellness*

**Physical dimension** (approximations of Hettler's dimensions are shown in *italics*).

*Hettler's physical dimension recognises the need for regular exercise, a nutritious diet, and ongoing 'self-care'. The latter entails personal responsibility and care for minor illnesses, and accessing and using appropriate professional medical care when necessary. The physical benefits can also lead to psychological benefits for the individual.*

The relationship between feeling 'healthy' and pursuing health promoting behaviours, such as physical exercise, smoking cessation, avoiding excess alcohol, optimal nutrition and attaining sufficient sleep, are well established in the literature (WHO, 2003 & 2008; Marmot, 2005). The exigencies of caring for people with dementia, and the ways these can impact negatively on health and limit the capacity for pursuing health promoting practices, are also well documented. Significantly, some studies suggest that caring for a person with dementia can be more demanding than other types of caring (Ory, et al, 1999; Pinguart & Sorensen, 2003). Self-care (e.g. attending medical appointments, exercising, eating well, not missing meals or medication) is one aspect of the physical wellness dimension that carers report often having difficulty making time for, or not attending to (Burton et al, 1997; Pinguart & Sorensen, 2007; Schulz & Sherwood, 2008; Mestheneos & Triantafillou, 2005; Gusi, et al, 2009; Hirano, et al, 2011). Carers of people with dementia often experience a lack of sleep or the inability to adequately rest and recuperate. Nearly half of respondents in one study reported having their sleep disrupted three times a week or more (Creese, et al, 2008); a figure borne out by other studies (McCurry et al., 2006). Mausbach et al. (2007) found that dementia carers may be at increased risk of developing cardiovascular disease (CVD). Moreover, carers in general had modestly higher rates of mobility limitation and mortality than their non-carer counterparts (Fredman et al, 2008).

But the extent to which carers' physical health is affected by their role is still unclear. Some studies state that less than 40% of carers feel their physical health is affected by their role (Schulz & Sherwood, 2008). Other studies cite significant numbers of carers, up to 75%, reporting negative impacts on their physical health, ranging from reduced immunity, to back pain, to visits to emergency departments (Rubin & White-Means, 2009; Gusi, et al, 2009; Bauer et al, 2000; Schubert, et al, 2008).

## **Intellectual / cognitive dimension**

*The intellectual dimension encompasses creativity and the need to engage in stimulating cognitive activities. These can be used for personal development, education and the benefit of the community. Wellness, in this dimension, assists with problem solving, maintaining acquired skills, learning new skills and enables one to intellectually engage with family, friends and the community.*

Carers of people with dementia need to maintain their cognitive functioning for two very important reasons. From a 'wellbeing', or wellness, perspective maintaining and developing cognitive skills adds value to the carers' life and offers an opportunity for personal development and taking on new challenges. The exigencies of the caring role often mean that carers may be at higher risk of cognitive impairment themselves due to factors such as

depression, loneliness, social isolation, limited exercise and diet. Carers may thus lack the time or energy to invest in maintaining or developing their cognitive skills (Vitaliano, et al, 2011).

From another perspective, it is important that carers maintain the cognitive skills that are necessary for them to meet the needs of the care recipient. This is especially important as the dementia progresses and the carer has to be able to respond to the care recipient's behaviours and needs. Carers having impaired physical and cognitive health has been cited as factors in elder abuse (Goodrich, 1997; Jogerst, et al, 2000). In a relatively recent study, 39% of a sample of 180 carers had mildly compromised cognitive function. The care recipients of those demonstrating reduced cognitive function reported being treated more frequently with abusive behaviour (Miller, et al, 2006). These findings are not unique (De Vugt, et al, 2006). Both of these perspectives demonstrate the importance of maintaining cognitive wellness for both the carer and care recipient.

## **Social dimension**

*Hettler's social dimension encourages contributing to one's community. It advocates social communication as a means of improving one's lifetime experiences. This dimension also includes a focus on the environment.*

Caring for a person with dementia exerts considerable pressure upon the time and resources that are available for maintaining friendships, social contacts and support networks. Australian carers are often only able to avail themselves of a maximum of 20 hours respite care per week (K Carter & J Michailow, *pers comm*, 2012). The physical and mental demands of caregiving can, in many cases, leave those who want to maintain their social networks with limited inclination or energy to do so when the rare opportunity presents itself. Indeed, respite care is often utilised to undertake everyday tasks (shopping, paying bills, etc.) (Mestheneos & Triantafillou, 2005; Carter, *pers comm*, 2012). Thus carers often have limited opportunities to socialise with friends and family beyond the caring role (WFMH [undated]; Mestheneos, & Triantafillou, 2005; K Carter & J Michailow, *pers comm*, 2012; Ory, et al., 1999).

Feelings of social isolation are not uncommon in carers of both genders (Forbes, et al, 2011; Waite, et al, 2004; Russel, 2001; Pillemer & Sutor, 1992), as are depression and anxiety (Schoenmakers, et al, 2009; Schulz & Sherwood, 2008; Belle, et al, 2006; George & Gwyther, 1986; O'Rourke, et al, 2003). Mental health issues, such as stress, depression and anxiety, can be exacerbated by the isolation caused by caring, or by the progression of dementia in the care recipient. Diminishing opportunities for socialising can also influence disease outcomes. A number of models suggest social networks can both positively and negatively influence health behaviours such as smoking, diet and adherence to exercise and medication regimens (Uchino, 2006). Another important aspect of being a carer for a person with dementia is that, because the role is constant, it can change how carers perceive themselves. Being a carer can give rise to a sense of 'biographical disruption', where the social dimensions of the carer's previous life are reshaped by the changing paradigms of the dementia dyad (Hasselkus & Murray, 2007; Lawton, 2003).

## **Spiritual dimension**

*Hettler's spiritual dimension recognises the search for meaning and purpose in human existence, while acknowledging the oscillation between peaceful harmony and challenging moments.*

The role of spirituality and religion in health is a source of considerable debate amongst health professionals, especially as all sides readily admit the difficulty in defining concepts which may be distinctly subjective (Doherty, 2006; Koenig, 2007). Proponents contend that spirituality and religion can be positive for health (Timio, et al, 1999; Koenig, 2007 Eckersley, 2007; Gwyther, 2006). Critics note that evidence of a positive correlation is 'weak and inconsistent', with study designs and confounders, such as diet and lifestyle factors, making it difficult to ascribe effects (Sloan, et al, 1999; Jackson, 2007) although some studies reporting a positive effect of religiosity acknowledge these limitations (Choi, et al, 2008; Rabinowitz et al., 2009). Degrees of religiosity and spirituality also vary widely across cultures and individuals. Much research has been focused on countries such as the US, where participants may be more demonstrative in their spiritual and religious practices, and thus it can be difficult to generalise these findings to other countries (Koenig, 2007).

Spirituality and religion, while not a choice for all, can provide context, purpose and meaning for life to many (Hettler, 1976), especially at difficult points in life. Despite a lack of empirical evidence, it must be noted that both spirituality and religion are often cited by both patients and carers, across a range of medical disciplines, as occupying important places in their lives and throughout their illnesses (Penman et al., 2006; Desai & Grossberg, 2011). Spirituality and religion are cited as sources of strength, comfort, resilience and support (Stuckey, 2003; Browning & Kendig, 2010; Jolley et al., 2010). Some studies have reported that carers have felt a sense of increased spiritual satisfaction, connection to their care recipients and contentment through their experiences as carers (Netto et al., 2009; Stuckey, 2003). Spirituality and religion can also perform other functions in the carer / care-recipient dyad, such as providing a familiar or ongoing shared experience such as attending church (Hasselkus & Murray, 2007).

While not explicitly stated in the literature, the practicalities of caring are likely to also impact upon the spiritual health dimension through a lack of time or resources available to attend church or to enact spiritual practices. The inability to attend shared spiritual practices (such as church or bible group) is, moreover, often an opportunity lost to socialise (K Carter & J Michailow, *pers. Comm*, 2012).

## **Emotional dimension**

*Hettler's emotional dimension recognises an awareness and acceptance of one's feelings. It also includes feeling positive and enthusiastic about one's life. This dimension covers: stress; coping/mental health resilience; access to support networks that include professional mental health care; informal support such as friends and family; and access to respite care.*

The emotional health dimension is perhaps the most dynamic of those explored in this brief review. Changes in any of the other dimensions are likely to impact on carers' emotional health. Extended periods of time spent caring, lack of respite care, an inability to deal with unmet health needs or engage in intellectual activity, or an inability to relax or obtain adequate sleep can all impact negatively on emotional health. There is an extensive body of evidence that

reports how emotionally demanding caring for a person with dementia can be (Savage & Bailey, 2004; Papastavrou, et al, 2007; Leggett, et al, 2011; Perren, et al, 2006; Roepke et al, 2011).

Other common issues affecting carers' emotional health include a lack of family recognition for their efforts, having unrealistic expectations of the dyad, or self-critical perceptions about the level and quality of care they are providing (Ashworth, 2000; Mestheneos, & Triantafillou, 2005; Dohner, 2006). As noted previously, the constant demands of the role can mean carers experience 'biographical disruption' in the social wellness dimension, but these impacts are not limited to one wellness dimension; carers' former lives and sense of self can be subsumed into the role of care provision, and this has obvious impacts on their emotional wellness (Walters, et al, 2010; Hasselkus & Murray, 2007). Changes in the care recipient's personality or mood (including aggressive, inappropriate or challenging behaviours) as the dementia progresses can be a source of emotional distress for carers. Inappropriate expressions of intimacy and sexuality can be especially distressing for carers (Ward, et al, 2005).

From another perspective, carers may experience emotional benefits from their role. Many carers attest to the positive experiences they have, in spite of the demands that caring places upon them. These include opportunities to bond, re-live experiences, and feel like they are contributing to the care-recipients' quality of life (Andren & Elmstahl, 2005; Butcher et al., 2001; Peacock et al., 2010). Carers' positive emotional experiences have been posited as a way to maintain the dyad while reducing other burdens upon the carer. Highlighting the potential for interaction between the wellness dimensions, Pinguart & Sorensen (2003) reported that carers with positive emotional experiences of care provision had reduced depressive symptoms and a heightened subjective sense of wellbeing.

### **Vocational / Avocational dimension**

*Hettler's vocational / avocational dimensions emphasises satisfaction and enrichment through work or hobbies.*

Having a meaningful and rewarding career can be very important for health (WHO, 2003 & 2008; Marmot, 2005; Wilkinson & Pickett, 2009). Caring can not only impact on the time available for the activities most people take for granted, such as socialising, exercising, relaxing and sleeping, it is also extremely disruptive to maintaining a career or having time for hobbies. Carers often take holiday or sick leave to look after their care recipients (Robison et al., 2009; Eldh & Carlsson, 2011; Wang et al., 2011). In one study (Ory, 1999), over half of all carers had taken time off work to provide care or perform care-related duties. O'Shea (2003) found nearly two thirds of carers had amended their work practices in order to provide care resulting in both disrupted work and financial loss. Ory et al., (1999) also reported that carers often had to forgo leisure or hobby activities: a finding that is reflected in other studies (Covinsky et al., 2001, Cahill & Shapiro, 1998; Golodetz et al., 1969).

### ***Conclusions arising from the literature on the impact of caring on the dimensions of wellness***

It would be incorrect to assert that carers of people with dementia are always affected negatively across the dimensions of wellness discussed above. As mentioned, numerous studies report carers experiencing positive benefits from their role. However, it is also true that there is

a considerable body of evidence articulating how carer health is negatively affected by their caring. These dynamics are not mutually exclusive, and are often constant aspects of caring for someone with dementia. Carers do experience social isolation, emotional distress, depression and illness as a result of their caregiving, but in the studies examined, the majority reported that carers also assert that they are happy to continue with the role. In order to prevent the emergence of more of Fenger & Goodrich's (1979) 'hidden patients', it is incumbent upon the health profession and policy makers to develop a better understanding of the most effective interventions to support carers to maintain the health, dignity and quality of life that they deserve. This will be the focus of the next component of this narrative review.



## *Carer interventions*

Recognising that caregiving for people with dementia can have a deleterious impact on carer health, carer intervention studies trialled over the last two decades have largely aimed at ameliorating or minimising the deleterious health impacts arising from care provision, and/or provide carer support services, in a format that is more convenient or reflective of carer needs.

### **Broad issues raised in meta-analyses of interventions with carers**

Systematic reviews defined carer interventions in numerous ways: from 'psycho-educational, support, multi-component and other' (Parker et al., 2008) to 'psychosocial', (Van Mierlo et al., 2012; Hudson et al., 2010; Brodaty et al., 2003 & 2009), 'educational and supportive strategies' (Thinnes & Padilla, 2011), 'cognitive-behavioural therapy (CBT)' (Vernooij-Dassen & Downs, 2011), 'psycho-educational, CBT, counselling / case management, general support, respite, training for the care recipient, multi-component and miscellaneous' (Pinquart & Sorensen, 2006), and 'support groups, respite, psychosocial, multi-component, family support, psycho-educational and care co-ordination' (Eagar et al., 2007).

An overarching theme of many of these reviews, and the meta-analyses, is that interventions are often shown to be of limited benefit to carers. This is largely attributed to methodological issues (study design, heterogeneous study population, short follow up, difficulty in measuring effects, complex or ill-defined outcomes, etc.) and difficulty in measuring outcomes. As one review commented

*... it is not surprising that they [reviews of interventions] draw different and conflicting conclusions (Eagar, et al., 2007).*

A key factor behind the range of study findings is the diverse social and health characteristics of carers of people with dementia (reflecting the general population from which they are drawn). This diversity presents considerable challenges in comparing and evaluating interventions aimed at improving carer wellness. It cannot be assumed that interventions reporting negligible benefits for carers are ineffective. Rather, they may not be measuring accurately the benefits that carers experience, or measuring the relevant benefits experienced. As Pinquart and Sorensen (2006) point out

*... there is [a] continued need for improvement in the quality of interventions.*

Parker et al.'s meta-analysis (2008) provides an instructive example of the issues prevalent in analysing carer interventions. In their comprehensive review of interventions (including 34 RCTs), they noted that a wide range of outcomes were measured including depression, self-efficacy, burden, and subjective well-being. They also noted, with some surprise, that there was a dearth of studies measuring 'health' and 'quality of life' outcomes, despite carers often reporting a range of health issues associated with caregiving (Parker et al, 2008; Brodaty et al, 2003; Cahill & Shapiro, 1998). This deficit was attributed to the difficulties in conducting longitudinal studies which capture these types of data accurately, and in identifying pre-existing illnesses before the 'care trajectory' begins (Ducharme et al., 2011). Because carer interventions are so complex, involving social, medical and environmental issues and factors for both the carer and care-recipient, there are obvious challenges in applying them with the rigour and limitations of an RCT (Eagar et al., 2007).

In their review, Parker et al. (2008) found that interventions which only included referring carers to support groups, offering peer support or providing educational materials, were of limited benefit. They recommended that future studies should include outcome measures which are less 'ad hoc' and that RCTs should be well defined and have adequate follow up periods.

### **Psychosocial interventions targeted at carers**

Psychosocial interventions, including education, training programs, support groups and counselling, capture a diversity of practices aimed at improving the wellbeing of carers (Brodaty et al., 2003; Pinquart & Sorensen, 2006). In a 2003 review of 34 psychosocial interventions, Brodaty et al. found carers had accrued 'modest but significant' benefits from the interventions across a range of measures. Brodaty noted that unsuccessful interventions included short-term education, support groups as the sole form of intervention, and limited duration interventions that did not include ongoing long term contact; findings also highlighted by Parker et al. in 2008. In one psychosocial intervention, carers were largely positive (90% in each arm) about a multi-strategy intervention that included carers being randomised to four programs: cognitive stimulation, dyadic counselling, dual supportive seminar and early-stage day care (Quayhagen et al., 2000). The authors acknowledged that although the programs were different, they shared a lot of similar content, making it difficult for quantitative differentiation in the assessment of effectiveness. They also noted that the relatively short duration (8 weeks) of the intervention may have limited uptake of program content, and also made longitudinal assessment impractical. These are issues which highlight the difficulty in planning and implementing interventions. In a recent review of 43 interventions, while acknowledging that the 'quality of evidence was limited', Thinnis and Padilla (2011) suggested that a multi-component approach of support and education was of most benefit to carers. However, they again highlighted that carer burden was not defined in a standardised way making comparisons of efficacy difficult.

### **Respite care interventions**

Increased respite care has often been posited as one of the most pressing needs of carers of people with dementia. It often comes high on lists of recommendations or policy areas for improving the quality of life of carers (Jorgensen et al., 2010; Mestheneos, & Triantafillou, 2005; Bruen & Howe, 2009; ACNS, 2011). Adequate or appropriate provision of respite care should, in theory, allow for improvements across a number of the wellness dimensions. However, previous studies have suggested that respite care may provide limited or only temporary relief to carers (Flint, 1995; Gottlieb and Johnson, 2000). Lee and Cameron, in their 2004 review of three respite care RCTs, found 'no significant effects'. However, they commented that this may not reflect a lack of benefits to carers, rather, this may be the result of a lack of high quality research in this area.

Of note is that the well regarded multi-component *Resources for Enhancing Alzheimer's Caregiver Health (REACH)* studies did not include respite care (Gitlin et al., 2003; Lund et al., 2009). The review by Parker et al. (2008) also excluded studies incorporating respite care. However, Schacke and Zank (2006) found respite care to be of some benefit in reducing specific aspects of carer burden, especially around managing work commitments. These findings, and caveats, accord with those of Mittelman et al. (2006). Eagar (2007) notes that respite care is often provided in various formats (short-term, day care, etc.) which can change the perceived

benefit. Another potential confounder is that carers make use of their respite care in very different ways, and they are not always satisfied with how that time is spent by using the time (eg. to attend to other caring duties while the care recipient is being looked after).

A recent study found that 46% of the carers surveyed were less than satisfied with their respite experiences, with this particularly applying to those who were depressed as they may not be in a position to make optimal use of the respite time (Lund et al., 2009). Therefore, respite interventions, to depressed carers, may have limited opportunities for improving their wellness. Other issues that could impact on carers accessing respite is that, within the Australian context, there are a number of respite schemes which have differing eligibility and fee structures making it confusing for carers (Bruen & Howe, 2009). Empirical evidence notwithstanding, the importance of respite to carers was highlighted in a qualitative research study on carers' perceptions of, and experiences with, respite. One carer poignantly highlighted that *I don't know what I'd do if it [respite care] went* (Ashworth, 2000).

Context to this was provided by the research team

*The sheer physical and psychological exhaustion [of carers] was evident and so was the despair, all the more so because the only end in sight was the death of the dependent* (Ashworth, 2000).

Stirling et al., (2010) assert that carers' 'felt' need for assistance should be a sufficient indication of their growing stress and thus deserving of respite care or other support; even if the respite service provider assessment does not suggest that the carer has 'unmet' needs.

## **Exercise interventions**

As noted above, carers of people with dementia often lack the opportunity or are unable to make time for exercise. The physical demands of caregiving vary widely. Von Kanel et al., (2010) found that carers were less physically active than the non-carer control group, and thus had a higher cardiometabolic risk. Gusi et al., (2009) found that while the carers studied were physically strong, the female carers were more vulnerable to back injuries - something which could potentially compromise their ability to continue in the role. Studies have suggested that improving physical activity levels may have a positive effect on health and quality of life (Hirano et al., 2011).

There have been a number of successful exercise interventions for carers of people with dementia. Castro et al., (2002) found participants experienced less perceived depression, burden and stress after a taking part in a 12 month exercise intervention. The researchers did caution that their sample may not reflect the general population of carers since those tested were well educated and mostly Caucasian. Moreover, being self-selected, the participants may be more inclined to take part in exercise when supported to do so. Some of these limitations were also echoed in another study that achieved positive outcomes for carers (Janevic & Connell, 2004).

A moderate intensity exercise intervention also achieved 'notable' reductions in psychological stress, but limited gains in fitness (King et al., 2002). These studies all had different outcomes (eg. cardiometabolic risk, carer burden and stress reduction) and, as has been previously noted, are dependent on a range of factors (eg. a lack of pre-existing medical conditions, access to respite care, predisposition to engaging in exercise, access to technology).

Interestingly, results from a Brazilian exercise intervention targeting care recipients suggested that exercise was effective in not only reducing their neuropsychiatric symptoms but also in attenuating burden in their carers (Christofolletti et al., 2011). There may be opportunities for future research on exercise interventions for care recipients to also include carers thereby involving both members of the dyad with consequent benefits to each (Pinquart & Sorensen, 2006; Smits et al., 2007; Thinnis & Padilla, 2011).

### **Technological interventions**

Technology may provide benefits to carers across a wide range of health dimensions. It may have the potential to reduce social isolation, provide access to services, and perhaps even support exercise and maintenance or development of skills. 'Telehealth' may be of particular benefit to geographically isolated carers (Glueckauf et al., 2007). Czaja et al. (2002) used telephones to provide formal and informal support services and contact with family members. While the intervention was deemed to be of benefit to carers, it must also be noted that using technology widely for this purpose may result in a spike in demand. For continued benefit, a concomitant increase in service provision may be needed.

Carers often express a preference for personal contact (Powell et al., 2008). The preliminary findings from a cognitive behavioural therapy intervention provided by telephone suggested that using this approach may be useful. The authors noted that further research was needed due to the small sample size and high attrition. A similar approach was used by Williams et al., (2010) although video coaching skills training (VCS) was augmented with weekly telephone calls. While the VCS study group achieved 'significantly greater improvements' across some psychosocial and biological measures than the control group, the authors concede that the groups were not randomised. One of the benefits of the Williams study is that it included 'objective' indicators of health, including blood pressure, heart rate and cortisol. Harmell et al., (2011) contends that this approach allows for the better definition of clinical outcomes for carers and also addresses the dearth of this type of data (also highlighted by Parker et al., 2008).

Another study with positive results provided carers with either an internet 'chat' or an internet 'video' support group and, not surprisingly, carers preferred the video option (Marziali et al., 2010). A relatively recent review found that results from technological interventions for carers were 'inconsistent', but they did have the potential to assist carers (Powell, 2008). This was a position also advocated by Thinnis & Padilla (2011), who acknowledged that interventions utilising technology have demonstrated limited positive benefits thus far, but could be of use for follow-up consultations, for example.

### **Other findings from carer intervention studies**

Selwood et al., (2007) maintain that individual interventions are more effective than group interventions, since interventions targeted at individual carers can be tailored to their specific needs. Indeed Marziali et al. (2010), examining the influence of factors such as personality and self-efficacy, suggest an individualised approach to interventions in order to effectively target specific carer needs. However, other studies note that group interventions can be of benefit in strengthening social support (Sorensen & Conwell, 2011; Eagar et al., 2007).

It is also important to note that while the carer population now numbers in the millions worldwide, many of the authors emphasise the need to tailor interventions to the specifics of the dyad (Thinnes & Padilla, 2011; Parker et al., 2008; Brodaty & Donkin, 2009). Moreover, Ducharme et al., (2011) also draw attention to the appropriateness of the timing of interventions, especially focussing on the beginning of the 'care trajectory'. Additionally, while it is widely acknowledged that informal caregiving in the community offers substantial economic benefits to society, there is a dearth of data on the cost-effectiveness of interventions (Jones et al., 2012).

### ***Concluding comments about carer intervention studies***

Carer intervention reviews tend to suggest that the evidence from carer interventions, as one review reports, is

*ambivalent or conditional. However, a significant minority of studies do conclude that interventions for caregivers are effective, albeit at various levels of evidence* (Eagar et al., 2007).

Intervention studies, as noted above, often have very different research questions or outcome measures which make it difficult to compare their efficacy. Studies which are narrow in focus may miss benefits to carers that fall outside the scope of their study question; conversely, studies which have a broad focus may lack the sensitivity to measure specific or subtle benefits.

### ***Directions from the literature for future carer research***

Numerous authors have acknowledged the need for more effective carer interventions (Brodaty et al., 2003 & 2009; Eagar et al., 2007; Pinguart & Sorensen, 2006). The major difficulty, with many interventions to date, is that they are targeted at specific aspects of carer need. This exploration of the carer experience, viewed through the wellness dimensions, highlights that carer health can be impacted negatively in a wide range of ways (eg. physically, emotionally, intellectually, spiritually, etc.). Moreover, negative impacts in one wellness dimension can have flow-on effects to other dimensions.

The literature suggests that interventions that target individual carers and multiple components of their lives are the most effective. In line with recommendations suggesting that multi-component carer interventions are more effective (Parker et al., 2008; Thinnes & Padilla, 2011; Gitlin et al., 2003; Elliot et al., 2010) it is suggested that interventions that target multiple wellness dimensions may be more effective in meeting the needs of carers.

Much of the focus of carer interventions to date has been on reducing the negative aspects of caring. It has been suggested that supporting and emphasising the positive aspects of caring may also be a direction for future interventions (Carbonneau et al., 2010). This holistic approach, acknowledged as perhaps being methodologically more complicated, will also require the ability to accurately measure the nature and outcomes of interventions.

## *Interviews and focus groups with carers*

### **Care workers**

Nineteen care workers or care worker managers participated in five focus groups across the five study sites. These focus groups sought information on care worker perceptions of how carers are impacted by their caregiving responsibilities, as well as the challenges that carers face. This aspect of the study provided context for the interviews with, and data provided by, carers.

### **Carers**

Carer participants were recruited from five aged-care service provider sites in the greater Sydney area. The study design originally envisaged 50 carers participating via a number of focus groups. However, only 28 individual participants, both current and former carers of people with dementia, agreed to be involved, with most (25) carers preferring to participate via a one-on-one interview. Three carers took part in one focus group. Interviews were conducted at service provider sites or by telephone. The interviews and focus group with carers generated over 40 hours of digital audio recordings. These were transcribed and thematically analysed.

The format of the one-on-one interviews and the focus group were semi-structured, with a series of open-ended questions that covered 5 areas of interest:

1. The impact of caring on the wellness of the carer:  
Initially structured around Hettler's six wellness dimensions, and then through nodes eg. diagnosis, care recipient (CR) health and behaviour, role of family and friends.
2. The support available for carers  
This component looked at support from both formal and informal sources.
3. Wellness defined  
How carers considered or defined wellness themselves - if at all.
4. Suggestions for achieving greater wellness  
What suggestions, if any, carers made about improving carer wellness.
5. Other findings emerging from the research (eg. cultural and linguistic diversity and dementia, and elder abuse).

Quotes from carers are included in the report. They are identified only as participants: P1-P28.

## *Main findings*

### **The impact of caring**

The impact of being a carer was explored through Hettler's (1976) six dimensions of wellness:

- physical [health]
- vocational
- emotional [mental health]
- spiritual
- social
- Intellectual / cognitive

Carers articulated how their caregiving responsibilities affected each of the wellness dimensions. Carers were impacted to varying degrees across these dimensions and within the dimensions. While only a small number were impacted across every wellness dimension, every carer was impacted in at least three of the dimensions (physical, emotional and social). This was largely due to a range of factors that are reflective of the diversity within the group of carers who participated in the study, and included:

- Carer's relationship with care recipient
- Carer's own health
- Care recipient's health and diagnoses
- Care recipient's behaviour
- Family dynamics
- Previous experience with dementia or other illnesses
- Progress of the care recipient's dementia

Eighteen of our 28 carer participants were spousal carers; the remaining 10 were caring for parents (or parents-in-law). The 'biographical disruption' that carers experience as they adapt their lives to the caring role can be very profound; their roles change from husband or wife, son or daughter, to being a carer; their work, family and social lives are increasingly shaped and directed by an illness that not only affects the care recipient, but themselves also. Carers adjust to the vagaries of the illness in different ways. Some of our spousal carers found adjusting to the caring role much easier than those caring for parents. For some carers, the transition was somewhat simpler than for others. One female carer referred to her mother as

*Her best friend.* (P3)

Another male carer (who had no children), said that he previously never had

*to worry about anything, I just worried about looking after me, and that was really simple.* (P16)

Becoming a carer for his mother caused him to reflect on the huge learning curve that the role necessitated. He recognised that this included having to undertake practical aspects of caring that he had never envisaged himself having to do.

*I don't have a problem with washing a woman, washing my mother is a different set of rules. You know, when I have to toilet my mother, that's going to be a different set of rules.* (P16)



Furthermore, carers found that being impacted in one wellness dimension often had flow on effects in other wellness dimensions. Unsurprisingly, the carers' experiences were not dissimilar to those related in the academic literature.

### Physical wellness dimension

Physical wellness encompasses both undertaking activities to maintain wellness, such as exercising regularly and following a healthy diet, to addressing health issues as they arise and obtaining professional medical attention when necessary. Carers cited the physical and temporal demands of caring as the two main reasons that precluded them from undertaking regular exercise. One carer commented that, in addition to having raised blood pressure, he had put on weight because he was not able to

*get out and go walking. (P22)*

Another carer, P9, had to forgo his daily bicycle ride, to which he attributed gaining weight; and having left it for a considerable time was unable to go back to cycling because he had "lost his balance".

Carers sometimes underplayed the health impacts that they felt were a consequence of their caring role. One carer commented that she felt caring had not

*had any major impact on my health. (P12)*

But, she later acknowledged that she had gained weight, because of all the "sitting" and having to forgo her sporting club and an active job. Another carer discounted the health impacts but indicated high blood pressure had become an issue (P3). Exercise, one of the main ways people maintain their physical functioning and health, in addition to having health benefits, often offered opportunities for social and family interactions which were sometimes precluded by the caring role. One carer

*use[d] to manage my nephew's soccer and cricket sides. But being out all day, and Saturday, it's impossible these days. (P22)*

Another carer was also involved with a sporting club

*And that was a social thing as well. That's declined as well. (P12)*

The study participants indicated that the adverse physical health impacts they attributed to their caring roles ranged from the relatively mild - *weight gain* - to quite severe - *heart attack*. The carers acknowledged that the demands of their caring role meant addressing their own health needs and maintaining their wellness would always be of secondary importance to addressing the health needs of their care recipient. Some carers would miss preventative health check-ups. The carer who had suffered a heart attack, while looking after his wife, articulated it thus

*she's my priority... that's... that's my job, is to look after her. She can't look after herself, so somebody has to take responsibility... and I've taken it. (P10)*

A number of carers had pre-existing health conditions and the demands of the caring role meant that they were not addressing their own health issues. The consequence of this approach, in the words of one carer who had diabetes, joint issues, a demanding job and family life, is that health issues



*just compound, and get worse and worse and worse. Just because I'm not addressing the situation as it arises. (P26)*

She articulated her reasons for not addressing her health thus

*my health and my wellbeing is the very last thing, at the bottom of the list. I just can't afford to, you know, spend any time on myself because it is taken up with having to take mum to geriatricians and [] things like that. (P26)*

Another carer, who was in remission from cancer, and also had a physical injury that required physiotherapy, acknowledged that she was neglecting her health. She was missing follow-up cancer checks and physiotherapy appointments. She was

*not actually going to appointments because I've had so much time off with my mum. (P27)*

Missing appointments for medical care was not solely determined by the health needs of the care recipient. This carer was acutely aware and conscious that attending medical appointments with her mother meant taking time away from her work; something she felt very guilty about.

The carers, by and large, felt that they had their physical health impacted, to varying degrees, by their caring role. While it is difficult to be definite about ascribing a causal relationship, the perceptions of these carers correlate with those found in the literature, highlighting how carers can have their physical health impacted by their responsibilities, as well as how health issues, when neglected, could be compounded over the longer term.

### **Emotional / mental wellness dimension**

Hettler's definition of emotional wellness includes being able to manage feelings effectively, and to arrive at personal choices and decisions based upon the integration of feelings, cognition and behaviour. It also includes a

*realistic assessment of one's limitations, development of autonomy, and ability to cope effectively with stress (Hettler, 1976).*

These three aspects of Hettler's emotional wellness dimension can be impacted by the caring role, and these in turn, can affect an individual's overall mental health. The emotional wellness dimension therefore provided a useful lens through which our carers' mental health could be assessed.

Stress and mental anguish were common features experienced by our carers. They largely attributed stress to having to meet the needs of their care recipients and trying to maintain a semblance of normality with managing other responsibilities; whether it was working and being a carer (P10, P22, P26, P27), dealing with challenging care recipient behaviour (P6, P17, P25), the health and wellbeing of the care recipient, and especially as many carers are themselves advanced in years, the carer's own physical limitations. One carer felt:

*there's always the worry that, ahm, well she's had a couple of falls in the last couple of months. The second time I called an ambulance because I could not lift her off the floor. (P5)*

The challenge with stress is that it is sometimes difficult for carers to recognise or address it, because the factors that determine carer stress levels are often beyond their control. Two carers in the focus group illustrated this point very poignantly when talking about stress and their quality of life

*P8: you don't have a life*

*P6: you don't really, because you are worried the whole time*

*P8: you live, you function according to the other person, when it's needed you have to be there to do it*

This sentiment was echoed by another carer who felt she  
*was stressed all the time, and I still am. (P17)*

And while she could not be specific about how this was affecting her, she felt that the  
*stress must have an enormous impact. I don't think I am functioning as efficiently as I used to, and as I'd like. (P17)*

The carers are feeling stressed, but it is often the care recipients who are the object of their concern

*The worry... just the stress of being constantly worried about her. (P26)*

At the upper range of the stress spectrum, the pressures of caring resulted in two of the carers experiencing psychological breakdowns. One carer, again illustrating how impacts in one wellness dimensions can impact on others, articulated how pressures in other aspects of her life, combined with her own deteriorating physical health proved to be too much. The resultant breakdown

*was a culmination of a whole year of stresses. (P6)*

Another carer, with a limited support network, had taken on the whole responsibility of caring for her husband. She finally "buckled" under the pressure and reported a psychological breakdown. The only positive about this was that it was a catalyst for her  
*speaking to somebody about respite. (P28)*

In another example of the interplay between the wellness dimensions, this carer felt that her stress was the main reason why the nearly three month old wound from a surgical procedure was not healing.

*I think it is stress, more than anything. Because I've got to be on my toes all the time, to make sure that [her husband] is OK. (P28)*

She had been on multiple courses of antibiotics, to no avail.

Carers are often so immersed in their responsibilities that they may not recognise the mental and emotional impacts they are experiencing. It is often someone outside the dyad who recognises the seriousness of the situation. As one carer recounted

*I didn't recognise [it], the community nurse did. She was the one that picked it up and said you've got, well actually she got me psychiatric help at one stage. I was that stressed out, I was going, I was gone. [ ] That's how bad, I didn't realise I was that bad. (P10)*

The most severe impact that being a carer can have on mental and emotional health is most profoundly illustrated by the example of two male carers who were looking after their wives. They were impacted to such a degree that they had both contemplated murder-suicide.

*I had it in mind to finish it all off. I thought I'd put her in the car and we'd drive off somewhere sometime, and finish it off. That's, that's the easiest way out. (P9)*

This was driven by the realisation that the impacts of caring and his own health issues meant he was no longer in a position to keep caring for his wife and that she would have to be placed into care. The guilt he felt was overwhelming.

The wife of the other carer (P23) became increasingly prone to violent outbursts, for which she eventually required hospitalisation. She was admitted to a general hospital. This was very distressing to the carer because general hospitals 'just can't cope' with people with his wife's condition. He indicated that even though his wife was in hospital he still had to be there to ensure she ate, drank and had her personal care needs met. Indeed, there are those within the healthcare system who recognise that hospitals have challenges meeting the needs of older patients, especially those with cognitive issues, complex conditions and co-morbidities (Hitchcock, 2015). P23's wife was subsequently transferred to a specialised hospital which was able to meet her needs. After twenty months of being a full-time carer, with limited support from friends and family on top of the trauma of his wife's hospitalisation this carer had reached his 'breaking point'

*if I'd had a gun, I'd have shot her and shot myself. Now that is an indication of how I felt at the time [ ] I was pretty low. (P23)*

The staff, at both hospitals, were very supportive and understanding of his situation. However, he did not feel able to discuss the true state of his mental health. They

*could see I was very emotional. I didn't tell them that I was suicidal, or contemplating murder for that matter, [ ] it's not something that you'd want to talk about anyway. (P23)*

These sentiments, which are indications of the stresses that these two carers were under, are not unique amongst carers of people with dementia (O'Dwyer, 2013).

## **Vocational / occupational wellness dimension**

All our Carers who were of working age were impacted vocationally by their caring responsibilities. In the early stages of the dementia, carers were often able to maintain their normal work routine and kept in contact with their care recipient throughout the day by phone (P26). Many of our carers spoke of the challenge of maintaining an effective balance between their work life and that of being a carer

*while I was still working, I was struggling a bit trying to manage the issues that she was having. (P18)*

For some it meant having to leave work for portions of the day to meet the needs of their care recipients. These ranged from attending GP and specialist appointments, organising service providers, to having to respond to medical emergencies

*I've had to rush over, at different times, take her to emergency rooms, and stuff, and you know, wait for hours in, at the hospital. (P27)*

As another carer articulated, these types of events are not uncommon.  
*I was at work, and I got a phone call, [ ] so I had to leave work straight away. (P28)*

Carers are often dependent on the goodwill of their employers for making these sorts of accommodations. And while our working carers indicated that their employers were supportive and understanding of their situations, it didn't stop them feeling guilty about the caring role impacting on their jobs.

For self-employed carers, the challenges of running a business around meeting the needs of their care recipient impacts on other aspects of their own wellness. A carer who operates a computer repair business indicated that he has to work when his care recipient is asleep and  
*I'll be up until 2 o'clock in the morning sometimes working on the computers because I need to get them done to go back the next day. (P22)*

For others, caring responsibilities sometimes necessitated the taking of extended periods of time away from work as carers' leave, annual leave, long-service leave or leave without pay.  
*I had to use my long service leave. So when I left I virtually had no long service leave after 26 years. (P3)*

The progress of their care recipient's dementia has meant that some carers made even greater sacrifices and gave up their work, future employment opportunities or their businesses altogether. (P12, P25, P10, P16)

Carers' dedication to their care recipients has sometimes meant having to make difficult choices concerning this aspect of their lives.  
*I had to make a decision to, ahm, either [ ] put him into a nursing home or give work away. And I chose the latter. (P28)*

And while this decision meant degrees of financial hardship for this carer, she  
*found that, that it was better for me to give work up and look after him because he was more, he was much more, ahm, in control when he knew that I was around (P28)*

Another carer, discussing the competing concurrent challenges of trying to run his business, be a carer, and address his failing health decided that selling his business was the only option he had, irrespective of the losses.  
*It was either sell or walk out. I was going to walk out at Christmas time if I hadn't sold. I had to, it just became too much. (P10)*

The care recipient's own employment situation could also have an impact on carers. One lady struggled with her husband continuing to work. His work formed a large part of his identity and their social life. When she had begun to notice that there were issues with his cognition she provided secretarial assistance to him, dedicating considerable time and physical and emotional energy towards allowing her husband to continue with his consultancy work. It was a  
*hassle for him to produce them (reports). And then for me to type them and re-type them and re-type them, so I was re-typing a million times. (P4)*

These efforts were not without consequences. She

*began to suffer what I thought was stress, [ ] I wasn't a stressy person, but I blamed stress and, the children came over one morning, and my hand was shaking so much I couldn't even type, and my feet, feet all swelled up, and I had ahm, Graves' disease, which I think can be brought on by stress anyway. (P4)*

There are considerable challenges for both the carer and the care recipient in having the care recipient relinquish roles, both vocational and avocational, and then having to meet the roles themselves, either financially or functionally. Care recipients sometimes have trouble accepting their limitations due to their dementia, but so too do carers.

### **Intellectual wellness dimension**

For the purpose of this study, the intellectual wellness dimension was broadened to include creative hobbies and pastimes that carers engaged in. The intellectual wellness dimension, reflecting impacts on other wellness dimensions, was also an area where carers had made sacrifices to continue their caring responsibilities. This dimension was very important to the carers in the study. For some, this impact is both very tangible and intensely personal because it embodies or reflects an intrinsic aspect of themselves. The way some of the carers describe how caring has precluded their ability to pursue their creative and intellectual interests conveys a deep sense of loss. A female carer described the impact thus

*So whatever I was doing, little by little I was leaving them behind. My all.... I was into painting, into craft, into all sorts of things. Little by little I left them behind. (P8)*

A male carer who restored vintage motor cars indicated that his hobby allowed him to be creative, continue learning and was an opportunity to be social.

*I used to see those guys regularly, go down to see them, and do workshops and paint shops and do work with them and learn a bit, and ahm, you know, they were good technical contacts which I enjoyed. Well, I've lost all of those. (P2)*

The often complex range of factors and dynamics that determine so many aspects of carers' lives can have impacts upon multiple dimensions of wellness. The illuminating case of a carer who gave up work to look after her husband exemplifies this. She indicated that she would love to go back to study, but that wasn't possible in the near term because of managing time, finances and her husband's dependence on her. There are challenges in fitting available respite care into scheduled events like lectures and classes (this holds for commonplace events such as attending medical appointments, and even her dementia support group). Her husband gets very disorientated if she is absent for extended periods of time. She is now reliant on a carer's pension, so her financial situation also precludes her from pursuing her intellectual interests even if her husband did not require her constant company. (P28)

Even for a care recipient who is in the early stages of dementia, the changes in their interests and personality often means that they lose interest in former intellectual activities making these interests difficult to pursue for their carers also. One carer related how attending live music concerts and the theatre were common experiences that she and her husband both took great pleasure in. However, she no longer made arrangements for these events because her husband did not enjoy them now

*and that really spoils my enjoyment of it. (P17)*

The suggestion that she could attend these events alone or with friends was discounted because these were always shared experiences.

The importance of intellectual wellness cannot be minimised. For many carers, their hobbies and pursuits, that form this wellness dimension, are an intrinsic part of their identity but they also provide opportunities for social interaction, personal development and cultural experiences. One former carer was able to resume his hobbies after a five year hiatus (his wife had been placed in permanent residential care), but this did little to overcome the profound sense of dislocation and grief that he still felt as a result of his caring experiences. The care recipient is predominantly the carer's focus (even after 3 years this was still palpable). (P9)

### **Spiritual wellness dimension**

Hettler's definition of spiritual wellness is worth quoting in full.

*'A person engaged in the process of spiritual wellness is willing and able to transcend oneself in order to question the meaning and purpose in his/her life and the lives of others. He/she is involved in the process of questioning all that is around him/her and has an appreciation for that which cannot be completely understood. This person seeks to find harmony between that which lies within and the social and physical forces that come from outside. Feelings of doubt, despair, fear, disappointment and dislocation as well as feelings of pleasure, joy, eagerness and discovery are part of this search for a universal value system. The person on a path towards spiritual wellness is learning to be tolerant of the opposites and contradictions that exist within his/her world and beliefs and influences of others. He/she is able to engage in the formulation of a systematic worldview, and system of values that give unity, purpose and goals to one's hopes, striving, thoughts and action.'*

This spiritual wellness dimension is perhaps the most and least applicable to the situation of carers of people with dementia, insofar as carers took considerable meaning and purpose from the caring role, but they did not articulate this as spiritual wellness, even though it closely mapped to Hettler's definition. Spiritual wellness was something that was clearly articulated by only one of the carers, who took great solace in regular meditation and spiritual practices.

*[ ] without that, that and my general and spiritual practice I think I'd be, you know, not coping at all. (P4)*

Religious and spiritual practice in Australia is usually culturally and socially more private than in the US, where the 'wellness dimensions' concept was developed. There is no doubt that the carers in our study felt a deep sense of purpose and derived considerable satisfaction in caring for their care recipients (P4, P16, P18, P22). However, the role also gave rise to other, more challenging emotions. Some carers indicated that they experienced feelings of self-doubt and guilt, much of which arose either from family members voicing concerns about their inability to provide appropriate care for their loved ones or they themselves doubting the adequacy of their own efforts at providing care; the following focus group conversation discussing this issue illustrates these feelings:

*P6: I've got all of my family around me not really thinking I'm doing the right thing. And it's total guilt the whole time. People lay it on you, [ ] guilt, guilt, guilt.*

*P7: we find the same at the (dementia carers) support group. All the people have that, have that experience (of guilt).*

## P8: Everybody

The self-doubt was posited as something that occurred because their social isolation meant they often had no one affirming that what they were doing was 'good-enough'. But, as noted, carers were also often able to find great joy and laugh at experiences they had shared with their care recipients, even when they were challenging. P21 recounted the challenges she experienced in undertaking 'outings', especially as her husband had a habit of 'escaping'. In an interesting role-reversal, he adopted a protective role over her in a large crowd, even though he was the person with dementia. She saw that he was in his 'element' and he derived great 'pleasure' from the experience of attending the Sydney New Year's Eve fireworks display - something that they had always shared. She had had her reservations at the start of the evening, but, reflecting on these sorts of experiences, she realised the importance of continuing these outings for both of them, even though they presented challenges for both of them.

*If we can, we do it. (P21)*

### Social wellness dimension

Hettler's definition of social wellness encompasses the importance of social interaction and engagement, effective communication among community members, and that these interactions are reciprocal, both for the individual and the community. Some of our carers demonstrated how positive social interaction was essential for both themselves and their care recipient but also how, for many, caring responsibilities limited their opportunities for social engagement, as the previous examples regarding the opportunities for exercise and socialising illustrated.

As one carer put it when asked about the impact on this wellness dimension

*What social life? (P22)*

His sentiments were echoed by another carer

*social life, what social life? You don't have a social life. (P10)*

This was a common refrain for many of the carers. The reasons for having a reduced social life were somewhat varied. For some it was a time issue

*as she got on with the dementia she wasn't able to be on her own... so I had to organise either respite or someone there to take my place. (P3)*

Another carer who was an organising member of a social club member realised that

*I can't do any more for the social club. Because it takes up too much time [ ] And I realise I need to put more time in with A (the care recipient). (P5)*

For others it was the physical logistics of caring

*I don't go out at night time, because if I go out at night time I've got to leave me son here with her, ah, they've got to be people to put her to bed, it's not a 1 person job, you know, you don't get a social life. (P10)*

Care recipients also had an influence on the social life and interactions of their carers. P24 could not travel to visit friends for lunches as much because of her husband's physical health; P17 had changed her social life and was having 'fewer outings' because her husband's behaviour was an 'embarrassment to some extent' (P17). She was aware that it was part of the condition but was uncomfortable having her friends exposed to it, highlighting how much stigma exists for people with dementia. Another carer, whose mother was part of an active seniors' social group, felt they were becoming uncomfortable in her mother's company as her condition progressed. While her own social life was somewhat limited by her mother's condition, she also realised the social group's reaction was impacting on her mother's social life. Some of our carers indicated that long-time friends disappeared  
*you don't you see them for dust. (P4)*

Other factors can also shape social wellness. Two of the carers who had forgone employment found that their social lives were also impacted by their financial circumstances. One explained it thus. Friends

*won't ring [] because we know she can't come because she can't pay for it. (P28)*

Conversely, other carers indicated that their friends were happy to interact with them and their care recipients. (P7, P21)

Other carers had to adapt their social lives to their changed circumstances  
*we have our social life on the weekend. (P27)*

As the aforementioned examples illustrate, being a carer of someone with dementia can often entail having to accept limitations on a normal social life. However, there is scope for carers to maintain their social wellness. Two of our carers, after availing themselves of respite services, were able to re-engage with friends and family, and go out to lunch or the cinema. (P18, P21)

### **Wellness defined by carers**

Wellness, defined by Hettler (1976) as optimal human health resulting from the dynamic balance between six health dimensions or dimensions, was a concept that few of the carers had readily considered or had applied to their lives. Hettler had, as his focus, an individual within a community. Our carers, when asked to articulate their perceptions of wellness, often focused on the wellness of their care recipient first. Their concepts of wellness were defined within the construct of the dyad. Carers perceived or defined their wellness in various ways: these ranged from their levels of 'patience' or 'tolerance' (P2), 'how I handle situations' (P27), with their care recipient, to 'stress' (P10), not having 'physical' or 'mental' health issues (P26), their own physical ability to provide care, to lift the care recipient or get them out of bed (P5), 'being able to exercise or eat well' (P3), to having good health, being active and enjoying 'company' (P24). Some of the carers also defined wellness by the changes or impacts caring had upon their lifestyles, such as not getting out, putting on weight (P22), or not being able to have independence and freedom (P12). Two of the carers perceived wellness in ways that were not dissimilar to those defined by Hettler. One opined that

*when I'm physically and mentally and psychologically, sort of, in sync or in wellbeing, well then I know that I can cope very well, much better with what life brings than when I'm not. (P4)*

For another, wellness was trying to maintain, as best as one can, a normal lifestyle by



*adapt[ing] with the health of various reserves, resources available to you, and information, to manage the condition as best you can... [ ] to keep in good shape, to be a carer for somebody with the condition. (P18)*

Being a carer of someone with dementia can be an immersive, overwhelming experience. Carers 'just get on with it'. Often they do not fully comprehend or are cognisant of the degree to which being a carer impacts upon them, or alters their life. One carer acknowledged that the interview with the researcher had given her considerable cause for reflection because, until going through each of the wellness dimensions, she had never considered how many aspects of her life had been affected by being a carer

*I must admit I've been on a bit of an emotional journey whilst I have been talking to you (P1)*

She also felt the interview was beneficial because, even though she had attended support groups and talked to friends, she had never been given the opportunity to talk at length about her experiences of being a carer.

## DISCUSSION AND SYNTHESIS

### *Challenges to Carers' Wellness*

Among the many issues that carers identified as impacting upon their wellness, there were four areas that stood out as particularly stressful. These were:

- Dealing with changed behaviours
- Accessing support services
- Family dynamics
- Interactions with health professionals

### **Dealing with changed behaviours**

A common thread running through the carer narratives was the impact and the difficulty they had in dealing with the changed behaviours of their care recipients. The carers discussed how these changes in behaviour, and the behavioural and psychological symptoms of dementia, sometimes presenting as the expression of frustration, anger and even aggression on the part of the care recipients, were perhaps some of the biggest challenges to their wellbeing that they faced. For some it was the loss of conversation with the person they had shared things with for much of their lives (P17, P21, P23), for others it was behaviours that were a risk to the care recipient and the carer: P9's wife set the kitchen on fire, as did P28's friend's mother. On other occasions carers experienced episodes or behaviours which were more confronting than many of them had ever envisaged having to deal with. P9 reported how his wife tried to jump out of a moving car while travelling to their daughters' home for informal respite: the daughters were so affected by this experience that they never felt safe enough to have their mother stay again, increasing the impact on P9; P6's mother became abusive at family gatherings; P21's husband tried to get off a moving train; P25's mother was constantly rude and aggressive. Not only were these events confronting in themselves, but their impact was magnified because they were the result of behaviours that were so out of character for the care recipient. One carer, reflecting on his having had to call upon the police to restrain his wife during an episode, described her as someone who was

*the gentlest, inoffensive person, never abused anybody, any of this sort of stuff... it was just a total opposite end of the [ ] behavioural spectrum. (P18)*

Carers had to learn how to deal with these events. Because

*if you panic, you are putting yourself into a complete syndrome of getting them taken away and all this sort of thing. And that creates even more stress for you. (P21)*

The unfortunate thing for many carers is that they had to learn tactics and skills to deal with changed behaviours by themselves. Carers indicated that they would sometimes get angry and frustrated with their care recipient.

*I feel guilty for yelling at her, why did I yell at her? [ ] So I go outside in the backyard and scream for a while. (P16)*

This carer, in an effort to assist him in dealing with his frustration, has also learnt some breathing and relaxation techniques.

Carers had to learn to accept that it was the illness that was the cause of their frustration, not their care recipient (P8, P6, P21). The experiences of other carers was sometimes useful in attaining that perspective: G indicated how important the support groups were to him in highlighting that it was not his mother talking, but *the disease talking.* (P16)

Carers who experienced anger and frustration at their care recipients' behaviour indicated that these emotions engendered further feelings of guilt and self-doubt. As another carer commented, you have to *learn a lot [ yourself] to manage the sickness.* (P9)

Dealing with changed behaviours is a stressful experience for many carers, and much of what they do to manage these situations is either trial and error, or trying tactics that have worked for other carers. Having a systematic or formalised method or educating carers in how to manage these sorts of situations is something that a number of our carers articulated would have reduced their stress and improved their wellness.

### **Accessing Support services**

Service providers and support services are of vital importance for carers. They offer education on dementia, assistance with a wide range of tasks, and provide services that can allow people living with dementia to remain at home with their carer for longer than might otherwise be the case. These services range from offering in-home and institutional respite, assistance with meeting the care-recipient's basic needs such as lifting and bathing, to assistance with household cleaning and shopping, and subsidised taxi vouchers and incontinence supplies. However, carers often carried on 'coping' by themselves. *It's your duty to do it. You do feel that way.* (P13)

Even when carers know that support services are available they do not always avail themselves of them, because *that's my job, [ ] to look after her.* (P10)

*My wife is not well, I'm here to look after her.* (P18)

Others were not ready to access services because they were still coming to terms with how the condition will impact upon them and their lives. Although they knew of the condition, and that help was available *you really couldn't believe, want to believe it. It had to be in the future, [the need] wasn't now.* (P13)

The result of this approach is that when carers take the responsibility solely upon themselves to look after their care recipient, it impacts upon their wellness. As the examples given previously demonstrate, they often push themselves to their physical and mental limits. When carers begin to experience difficulties in coping, they do not know where to turn or who to look to for guidance or support in relation to accessing services.

*you just don't know what's out there. And what you're entitled to or what she's (the care recipient) entitled to... there's, there's sort of, ahm, no information available like that.* (P27)

Some carers had very different experiences - some successful, some challenging and frustrating. Much of the success in being aware of, or accessing support services was attributed to luck, word of mouth and information from friends. As one carer indicated, it was 'very easy', when you had the correct contact details (P3). Another carer, frustrated at his inability to have different service providers return calls or follow up on requests voiced his disillusion thus

*I think they were only interested in the name, to have you on the books. [ ] Because they might get a grant or something for it, because you're on the books. (P9)*

While these lapses may be a result of oversights by individual staff members of service providers, they may also be reflective of the strength of demand for services that carers require. A negative experience with a service provider can shape the support services that carers utilise. One carer put his wife into respite care for 3 weeks. Instead of respite being an opportunity for him to rest and recuperate, it ended up being a traumatic experience for both himself and his care recipient.

*It was the worst thing I ever did for her. (P10)*

She had visibly lost weight and was highly distressed during showering - something that had never happened before (P10). The carer experienced so much 'guilt' about that episode that he vowed never to put his wife into care again.

Other carers had very positive experiences with their service providers (P3), and the care workers can become almost like family to the carers. These care worker-carer interactions can sometimes be the only social interactions some carers have as their social and family life shrinks as a result of their dedication to the dyad.

*[the service provider] almost became my family, and when K (husband) went in to care, that ends, it almost ends overnight, and I was devastated, I really felt I had no-one. (P20)*

This carer, while acknowledging that the service provider was really supportive of her, indicated that service providers have limited funds with which to support carers once their care recipient is placed into care. This is because aged care services are budget constrained and, in the words of one community care worker manager

*Operate on the smell of an oily rag. (CCWP9)*

Accessing Centrelink support services often involves filling in numerous forms and then benefits are only available or managed via the internet or at a computer terminal at a Centrelink office. The study had a number of carers who were accessing Centrelink services, and while they were all computer literate, some of them had difficulty in navigating through the system (P16, P22 P28). One carer had his carer's pension stopped because he forgot his Centrelink password and missed an electronic letter requesting additional information in his drop box (P22). This was a topic that also came up in the focus groups with the care workers. At a number of sites they indicated that some older carers were having difficulties with accessing government services like Medicare and Centrelink. One carer pleaded with a care worker to help fill out a lengthy form, because

*If you don't fill this out I am just going to throw it in the bin, my head is going around and around, I can't cope (CCWP3).*

Another carer had not applied for the Centrelink carer's pension that he was entitled to because completing the forms was so onerous (P16).

The internet is a valuable research, education and support tool for learning about services for many computer-literate carers (P28). But, as some of our carers indicated, other carers who are older than they are may not have ready access to a computer or possess the necessary computer literacy or research skills to access this knowledge (P16, P22, P28).

## Support groups

Carers do not always recognise that there are groups of people in very similar situations to themselves 'out there' who meet to support each other and share their experiences. For the carers who availed themselves of them, support groups were beneficial to their wellness for a host of reasons. They included allowing carers the opportunity to discuss their situations with like-minded peers. They also provided a forum for learning about the support services that are available to carers. One carer outlined how a man in her support group was 'struggling so much', but he didn't know that he needed to have an ACAT assessment or that services were available to him (P4). Carers often used support groups to share their knowledge and learn how to manage 'situations' or 'changed behaviours'. Attending support groups, as one carer acknowledged, enabled him to learn

*tolerance and patience and which I didn't even know I possessed.* (P16)

Carers were able to encourage others to experiment - one carer was able to encourage her husband to shower by drawing on his face when he was asleep. One of the most valuable roles of the support groups was to provide a sense of solidarity with someone 'who understands' (P4, P8, P16, P19, P21, P22, P28).

There were, however, some carers who found support groups were of limited benefit to them for many different reasons. Some, for example, who were caring for parents, found the support groups they attended didn't reflect their age group, or the stage of the illness of their care recipients (P1, P12). Others, recognising that they could have been of benefit, found that their timing and availability did not suit the ever-changing demands of providing around the clock care to their care recipients (P10, P28). One carer (P9), recognising that he needed help, arranged for his daughter to look after his wife so he could attend a support group. Upon his arrival he was informed that it had been cancelled, and was told they would let him know when the next one was. Even though he was in considerable need of assistance he never attended another support group again until his wife was placed into residential care. A carer who was instructed by her GP to find a carers' support group, reflecting on her own varied experiences with them, felt that support groups were absolutely essential for carers. While she acknowledged that some were less than perfect, she said that, in her experience, it was imperative that carers try a few support groups until they found one that suited their needs. This advice may have been useful to the previous carer.

While support groups may be helpful as a forum for providing information to carers, this information it is often 'drip-fed' and carers are dependent on the acquired knowledge of those who attend (P16). This carer indicated that the information he received through one service provider was as much as he had attained through attending four support groups over the previous few years. He could have saved a lot of time getting it all in one place.

## Family dynamics of carers: factors which can determine informal support

Family dynamics was one of the factors which some of our carers identified as having an impact on their wellness. There is a popular perception that families are drawn closer together during times of stress or illness. Carers who had positive relationships with their families were able to draw on additional resources and support, both for themselves and their care recipient.

*I find it deepens those friendships and relationships in, in that interaction of helping and caring. (P4)*

Even when family dynamics were positive, carers were sometimes limited in their ability to avail themselves of family support because of distance. P17 had two children, but her son lived in another state, and her daughter was living overseas. P27's eldest daughter, who was very willing to assist, lived in Queensland. Many of P10's family lived within NSW, but none in close proximity. He was also a 'sandwich carer' - in addition to looking after his wife, he had to look after his son who had had an accident at work, and then subsequently developed a chronic illness. A number of our carers were in similar situations of having to look after their partners and care for children: P21 has a son with a mental illness; P26 had a son with dependency issues, a husband on a disability pension through a work accident (which limited his ability to help at home), and she also had to look after a daughter recuperating from a broken leg.

Although we had a relatively small sample of participants, over a third (10/28) of our carers had strained and sometimes even hostile relationships with their families, their siblings, children, in-laws and even their care recipients. These family dynamics were a cause of considerable stress for those affected. These resulted in conflicts relating to provision of care, legal issues, relationship stresses and even impacts on their own health. P27 felt guilty about not just moving her mother into her family home but was also very aware that

*if I did that, that would break up my marriage. (P27)*

P6 recognised that her mother, who lived alone, needed someone to 'take over' or manage her affairs because of her cognitive issues. P6 had considerable difficulty in convincing her siblings (who mostly live interstate) that she should take on the guardianship, even though she was living closest to her mother, and she and her husband were interacting with her mother on a regular basis and could recognise the cognitive decline

*and that was the beginning of me just thinking 'I don't know if I can deal with this'.. because I had to fill forms in and have my siblings agree to what I was going to do, and so you are on the phone talking to them and they are telling you 'oh no, mum's alright when I ring her'. (P6)*

P27 had traditionally 'taken care' of her mother. Her siblings do very little to help her. One is upset by her mother's condition, the other is resentful of past 'slights'. Even though their mother is able to still live alone with assistance from P27 and the service provider, her siblings

*make me feel [ ] that somehow I'm letting mum down. (P27)*

P23 had a strained relationship with his wife's children. They, like the family of many of our carers, played a very limited role in assisting him in the care of their mother. He, like many of our carers, was completely overwhelmed by the situation and felt 'completely alone', especially as his own family lived some distance from him.

Some of the challenges that the carers had previously faced in their lives were able to be applied in different situations. One of the carers was able to utilise the skills she learnt in managing her son's mental health illness when her husband subsequently developed dementia. She had involved the whole family in her son's care - from educating them about the illness (through weekly lessons and therapy sessions for the whole family), to joining support groups and developing resources for families in similar situations. These skills were very beneficial when her husband's dementia was diagnosed. She had a ready-made action plan, and the family were 'primed' to support her (P21). Another carer (P16) had a job (before he gave it up to become a carer) which entailed a lot of networking and research skills. He said those skills were indispensable in looking after his mother.

### **Interactions with GPs and medical services**

Some of our carers found their interactions with health professionals and the medical system very challenging. The main areas of concern for carers were obtaining a correct diagnosis and having their own health and wellbeing supported throughout the caring journey. Family members, before they become carers, are usually the first to recognise that something is amiss. Some care recipients were sometimes unwilling to engage with health professionals to address their carers' concerns.

*she used to get quite angry when I suggested taking her to the doctor. (P23)*

Some of our carers initial concerns and observations were brushed aside by GPs. One carer who had noticed issues with her husband 6 years previously finally got a proper diagnosis and a care management plan in the preceding year

*they say there's nothing wrong. [ ] I knew something was seriously wrong [ ] but I couldn't get any confirmation from anyone who should have known better. (P17)*

She felt that the stress she experienced from having to deal with caring for her husband, cope with his changing behaviour, and her inability to convince his doctors that something was wrong, resulted in her becoming depressed and having to receive counselling. This situation was not unique. The two female carers in the focus group had their care recipients' deteriorating conditions explained away as the symptoms of 'old age' (P6, P8). The difficulty in obtaining a diagnosis, even when specialists were involved, led to feelings of frustration towards the medical profession amongst some carers. One carer, articulating her feelings about having to see specialist after specialist, in attempts to understand what is happening with her husband, said

*they are so ridiculous these doctors. They think they know everything. They don't have a clue. (P8)*

Another said

*If you don't have a diagnosis, you're flying in the dark. (P6)*

One of the other issues that carers face is that health professionals may be aware that a patient is experiencing symptoms of dementia but not be able to inform relatives due to patient privacy requirements.

*how many years had the doctor known that she was heading that way and not said a word to any [ ] relation. (P8)*

Even when GPs have had an extended and ongoing relationship with their patients they can miss symptoms of dementia (P26). Some of the GPs inability to pick up on symptoms of dementia might be attributed to the relatively common short consultation times, or care recipients masking their condition, either from family members or health professionals. One carer commented that her husband presented very well and 'fooled everyone' (P20). P18 noted how his wife was able to mask her condition with their doctor and friends, and when he raised concerns or highlighted behaviours, his credibility was questioned (P18). This situation was not unique. Another carer, commenting on his interactions with a number of family members who had dementia, noted that

*they had dementia, but they are not stupid. If I ask you a question, and you don't know it, but you know you should know it, you'd be able to get around it... and so can they. (P7)*

However, it must also be noted that research has also indicated that GPs may be reluctant to suggest a diagnosis of dementia (Philips, et al, 2012). Communications between carers and health professionals are not without their problems. Health professionals play an important role in supporting carer wellness in ways which they themselves may not always comprehend.

*They don't know how to communicate. They don't know how to explain the situation; they don't know how to give you some courage to keep going. (P8)*

When carers had concerns about their family members, they were confused or unsure about how to raise or discuss these concerns with GPs or specialists. P16 said that every speciality in life had its 'language', and if carers wanted to communicate effectively with health professional, it was necessary for them to

*learn the language of dementia. (P16)*

Carers have to make sense of often complex and challenging situations. Lacking the 'language of dementia' or a basic understanding of the condition means that some carers do not 'know which questions to ask' of health professionals.

An increase in dementia information support services, many of which are freely available online, means there are many more sources of information available to carers. But for some carers, not in the habit of conducting online research, the availability of such services does not mean they are accessible or useful to carers.

*Do some research? Yeah, well, what questions do I ask? (P23)*

Carers acknowledged that they were often in denial about the symptoms they were observing, and even when a diagnosis was forthcoming, there were still issues about accepting and managing the illness. Some carers, like many members of the community, can sometimes find their interactions and even the attitudes of health professionals quite intimidating. Sometimes carers, many of whom already feel guilt and frustration about their own perceived inadequacies in providing care, have these feelings compounded when interacting with health professionals, especially if their issues or concerns have been raised previously, or involved seeing multiple health professionals. P20's husband, in addition to his dementia, also had a complex range of health issues. She constantly had to 'battle' health professionals to have them recognise that her husband also had dementia. These experiences were most discomforting to her.

*Medical people are the worst, [the] most hurtful to carers (P20).*



Her sense of frustration with the medical profession was not uniform. Her own GP was very applied in her approach to addressing the carer's wellness needs. Recognising that she was having difficulties dealing with the situation, the GP told her

*He's got dementia, he's going to the [respite] cottage and you are going to a [support] group. (P20)*

Another concern for carers was that GPs were often unable to provide them with advice on how to maintain their own health or pick up on their own health issues. One GP, over the 11 years that he was treating a husband and wife dyad, never discussed any of the carer's health issues. The doctor

*didn't give me any advice, or anything really. (P9)*

There may be a number of reasons for this: the appointments were booked for the wife, who was the care recipient, so the consultations would have been focused on her; the carer did not raise any of his health issues with the GP, because his wife was his main focus (this was a sentiment expressed by a number of our carers); or the GP may also have been unaware of the health and wellness impacts of being a carer.

While the previous examples have demonstrated areas where carer wellness has been impacted by shortcomings of health professionals, there were a number of carers who had very positive interactions with their GPs and health professionals. For some of the carers these interactions were pivotal in supporting their wellness, often after they had reached a crisis point which they themselves did not even recognise. Two carers recounted how their doctors outlined what would happen to them (and their care recipient) if they did not start looking after their own health and wellbeing. One doctor, who was very familiar with the impacts of caring for someone with dementia, gave one of our carers

*some fairly strong advice about what I needed to do about looking after my health, and going and getting fit and eating properly. (P18)*

Interestingly, when carers were asked who they would take advice from on managing their own wellness, GPs were cited as the people they would be most likely to accept advice from on addressing their own wellness needs. As the previous examples illustrate, health professionals can influence how carers address their wellness needs - sometimes they need an objective opinion.

### ***Other issues: Cultural and linguistically diverse issues, and elder abuse***

While carers' wellness has been the focus of this research, some data from the study has highlighted issues that may merit further research. General practice and other medical services have already been discussed, but the relationship one carer had with her GP illustrates other factors that can have an impact upon carers. This carer felt that her GP was judging her for allowing her mother, who has dementia, to continue living by herself. Her perception is that the GP, who is of a different ethnicity to her, is quite 'traditional' when it comes to family. His 'judgement' is causing her stress. The carer cannot be certain whether the GP's 'judgement' is real or in her imagination. However, she is experiencing stress from it, and it is an example of why GPs and other health professionals may benefit from further education on cultural diversity and skills in managing patients with dementia and their carers, especially if patients and health professionals are from different cultural backgrounds.

People with dementia do not always live with their carer. As such, they may be exposed or come into contact with people who do not understand their condition or how it affects their behaviour. One carer was informed by a service provider that her mother, who has physical health issues that are managed by a community nursing team, was 'handled roughly' because of her 'behaviour'. People with dementia can sometimes exhibit behaviours which others may find confronting or challenging. This is an issue that carers have to deal with continually, but even though there may be challenges in learning how to manage such behaviours, they recognise that it is the 'illness' not the 'person'. There is an expectation that a health professional or service provider, knowing a client has dementia, would still afford them the same degree of care and respect that they afford other clients. That this was not the case suggests that there is scope for ensuring all health professionals and service providers are educated in the management and care of people with dementia.

From a broader perspective, it is well recognised that people with dementia, and their carers, can experience stigma, isolation and discrimination (Alzheimer's Australia, 2010). Some of our carers were embarrassed by their care recipient's behaviour and had curtailed their social lives as a result of this (P17). Care recipients were also, in the words of one carer concerned about being labelled with the 'mad woman syndrome' (P16). This may be why numerous carers indicated that many of their care recipients exerted considerable efforts to mask their condition (P4, P6, P16, P20, P26, P27).

### *Carer suggestions for achieving greater wellness*

Carers suggested a number of ways in which their wellness needs could be better supported. Education on dementia, for both carers and their families, was seen as potentially very important, along with education on the support services available. This material could be made available through GPs' surgeries, information packs, helplines and DVDs.

Additional education for GPs and other health professionals, on how to recognise and manage dementia, was also seen as being an important strategy, along with training for health professionals on recognising the health needs of carers especially as the latter are sometimes reticent about articulating these needs.

### *Addressing the wellness gaps with carers, carer families and health professionals*

Carers identified three areas where their specific wellness was being impacted by their caring responsibilities. When our carers described how they were being impacted by their role, it was commonly described as 'stress'. This stress was caused through the plethora of demands that are placed upon them. Reducing these demands could, carers suggested, improve their wellness.

#### **Carers**

The first area is providing carers with appropriate knowledge and skills about dementia and how to deal with the many new and challenging situations that they face. One of the carers,

reflecting a common sentiment, explained how the knowledge and skills they had acquired over their caring journey would have benefited them from the beginning.

*...if we had the experience that we pass on now [in support groups to other carers]  
... if we had that at the beginning. The stress level would have been so much lower.  
(P22)*

As noted previously, caring for someone with dementia can be very challenging. While there is a lot of literature available on the various aspects of the condition, one of the areas where carers struggled most was dealing with changed behaviours. Carers sometimes found themselves in very difficult situations which were not only confronting, but some of them also had the potential for harm to the care recipient or themselves. Therefore having knowledge is especially useful, especially for dealing with challenging situations.

*Forearmed is forewarned, you just, you don't panic as much. (P21)*

Carers often had to learn how to deal with these situations by themselves. While some were very adept, there were other carers who struggled, and this had a toll on not only their physical and mental health, but throughout the range of wellness dimensions. There was a clear demand for carers being trained in these areas. A number of care workers indicated that they receive ongoing training on how to manage care recipients' behaviour. They suggested that providing this type of training and education to carers could be beneficial, especially as the carers are the ones who spend the bulk of their time with the care recipient.

The other main suggestion our carers had was that they would benefit from education on accessing support services, the various dementia conditions (especially the different stages), and questions to ask health professionals. It was suggested that this could be provided through online training or via other media like brochures or DVDs. This sort of training would have to be provided in formats that were accessible to carers. The fact that most of our carers were unable to attend focus groups for this research suggests that the normal 'workshop' style that is often employed for providing education may not be the most suitable format for delivering information to carers of people with dementia. This point is clearly illustrated by the example of one of our carers; she had been offered education on the condition and accessing support services, but was unable to make time to attend. (P27)

One of our carers had great success in using a meditation practice for her wellness. It is *the most incredibly helpful thing, I don't think I would be sane without it. (P4)*

While teaching coping skills such as meditation may be of limited interest to all carers, it may be of interest to some.

## **Carers' families**

Carers also suggested that education should be made available to their families. Their hope was that this would allow other family members, especially where there is friction, to gain a better understanding of the condition and the impact that caring places upon the primary carer. In addition, this education might encourage other family members to provide greater assistance and support. The successful approach of P21, in educating her whole family about her son's mental condition, and how this model was later applied to educating the family and supporting her when her husband was diagnosed with dementia, suggests that this approach is one that may have wider application.

## General Practitioners and health professionals

Our carers also suggested providing dementia-specific training and education to GPs and other health professionals. It is hoped that training and education on dementia and dementia-related issues for health professionals would:

- facilitate earlier diagnosis of the condition;
- provide carers with knowledge and advice about accessing support services; and
- highlight to carers the importance of maintaining their own health and wellbeing.

## General Practitioners and dementia diagnosis

As noted previously, carers who had difficulties in obtaining a correct diagnosis at an early juncture experienced considerable stress through not being able to understand what was happening to their family member (P8, P17). If GPs were better able to recognise the early signs of dementia it would allow for earlier diagnosis and better management of the condition. This would have benefits for both carers and care recipients. There is evidence in the literature that GPs may require assistance in recognising dementia in the primary care setting (Philips, 2012; Pond, 2013). Furthermore, the recently released federal government report on dementia, *Thinking Ahead*, highlighted the need for training that emphasises improved *diagnosis, care and support pathways for people with dementia and their families and carers*. (APHREF, 2013)

## Informing carers about available support services and encouraging carers to access support and services earlier

General practitioners are usually the health professionals who provide ongoing primary care to both members of the dementia dyad – but not necessarily the same GP for both. As our examples illustrate, carers are sometimes reluctant to access services, often preferring to continue caring for their care recipient by themselves. Indeed, some of our carers continued in this fashion until a health crisis arose.

When asked who they would trust to provide health and wellness advice, and who they would be most likely to follow advice given to them, the three responses given were general practitioner, social worker and friend. The most common response amongst carers was that GPs were best placed to provide information to them about health issues, services and supports. The reasons given were that GPs occupy a position of trust and have an understanding of the potential health impacts of the caring burden on carers. While it would be beyond reasonable expectations to assume that GPs could provide information on all the support services that are potentially available to carers, they may be in a position to provide information on basic services and supports. This information would need to be provided in a way that highlights to carers how important this information could be to their wellbeing. One of the carers, talking about how useful an information folder provided by GPs to carers of people with dementia would be, said he was

*darn sure it would be [a] great help to them (to carers). (P10)*

This carer was one who was under considerable strain. He attributed his numerous health impacts to his caring role and, as mentioned previously, was about to walk away from his

business. His wellness was improved by the intervention of a number of health professionals convincing him to start taking better care of himself. Therefore, it is important that health professionals

*don't hand them the folder and say it's all yours, you know, hand them the folder and say, this is where you start. You know, you ring this number and ask for help and they'll put you through the steps. (P10)*

While the carers indicated that GPs would be ideally placed to offer information on support services and resources to carers, this study has highlighted that the surfeit of information does not always get to those that need it, or when they need it. Many of the carers indicated that they knew of other carers through support groups etc. who were in much more challenging predicaments than they themselves were. Therefore any information, no matter who provides it, that is able to target 'hard to reach' carers could be of great benefit.

### **Informing carers of the need to maintain their own health and wellbeing**

As the previous paragraph and other examples have illustrated, carers sometimes need an objective perspective offering 'some fairly strong advice' (P18) on the necessity of addressing their own health and wellness needs. This has implications, not just for the carer, but also for the dyad, because healthier carers are able to maintain the dyad for longer. Our carers have indicated that they are sometimes reluctant to articulate their own health and wellness needs. Although carers want to maintain caring by themselves for as long as possible, they also benefit from seeking support services such as respite at a much earlier juncture in the caring journey (P18, P20, P21).

## CONCLUSIONS AND RECOMMENDATIONS

While many of the findings of this small study are not new, they do serve to highlight the fact that carers of people with dementia are still experiencing multiple impacts on their own wellness as a result of their caring role. This is despite decades of growth in services aimed at supporting dementia dyads and an increased awareness of dementia amongst health professionals as a result of education and higher prevalence of the illness due to population ageing.

The fact remains that maintaining and supporting carer wellness is both challenging and complicated, especially as every carer's situation is different. Carer wellness is a product of the interaction and impact on the carer of all the dimensions of wellness, and is shaped by the carer's family, their own health and that of the care recipient, as well as a wide range of social and personal circumstances.

This short qualitative study has also suggested areas where carer wellness could be supported and improved. It has highlighted the gaps in knowledge and support that carers currently face. The examples of carers who were able to achieve better wellness outcomes, through their own efforts or through the intercession or intervention of others, demonstrates that there is scope for improving carer wellness. These interventions, while often very personal pleas to the carers from health professionals and other interested parties, to address their wellness needs by taking better care of their health, or accessing support services, could broadly be defined as educational in nature. The carers also articulated that they would benefit from education: education on the resources and support services that are available to them; education on dementia and what to expect; education for family members on the challenges of caring for someone with dementia; and education for GPs and health professionals on how to recognise and support the wellness needs of carers of people with dementia.

### *Limitations of this work*

While this study had a relatively small number of participants, the data provided by the participants accords with other published material on the experiences of carers of people with dementia. It was originally envisaged that the carers would mostly participate in focus groups, but citing reasons of privacy or an inability to attend a focus group due to caring commitments, only one focus group occurred. However, comments from other interviewees were fed back during the individual interviews to try and replicate the focus group experience and see whether the experiences being relayed were common amongst carers. While the carers offered a considerable diversity of opinions and experiences in their interviews, many of the themes that emerged from the analysis were common. The focus groups with the care workers also served to provide context and to validate the data from the carers.

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# APPENDIX

## Participant Information Sheet and Consent



Approval No Ref#2012-7-11

## PARTICIPANT INFORMATION STATEMENT AND CONSENT FORM

The University of New South Wales (School of Public Health and Community Medicine), HammondCare, Queensland University of Technology, the Consumer Dementia Research Network and the Dementia Collaborative Research Centres are undertaking this project entitled: **“Beyond respite: designing effective wellness programs for carers”**

You (*i.e. the research participant*) are invited to participate in a study of the wellbeing needs and limitations of carers of people with dementia. We (*i.e. the researchers*) hope to learn about what carers want and need to improve their wellbeing. You were selected *as a possible participant in this study because you have current or previous experience as a caregiver of a person with dementia.*

### **Description of study and risks**

If you decide to participate, we will invite you to attend a focus group or a one-on-one interview at the HammondCare Clinical Training Centre at HammondCare or at another suitable location. At this focus group or interview, a moderator will lead discussion with you and other carers on topics such as the concept of wellbeing, activities that may improve wellbeing, how you feel about your own wellbeing, what wellbeing activities you undertake and what factors prevent you from undertaking wellbeing activities.

Participation in the focus groups or interview may involve you discussing your own caring experiences. This may be difficult for you. The moderator is able to stop the discussion if you find this difficult and do not want to continue the discussion. As participation in this project is voluntary, you are not obliged to participate nor are obliged to contribute any information that will upset you.

During the focus group or interview the moderator will take written notes of the discussion. In addition, we will also make an audio recording of the discussion for later analysis. You will not be identified by name in either the written notes or audio recordings.

We expect that each focus group will be no more than two hours in total. A number of focus groups will be scheduled at different times. Therefore, you are welcome to select a group that is the most convenient for you to attend. We also understand that you might like to participate in our study but that it may not be easy for you to attend a focus group in person. Therefore, we will also have some teleconference focus group sessions or one-on-one in person or teleconference interviews available, so that you can participate via a local call using your home phone.



We hope that conducting these focus groups and interviews gives us a clearer understanding of the needs and limitations experienced by carers of people with dementia. This will help us design accessible and suitable wellbeing strategies for carers, like you. Such strategies may or may not directly benefit you but the strategies may provide benefit to other carers in a similar situation to yourself. We cannot and do not guarantee or promise that you will receive any benefits from this study.

### **Confidentiality and disclosure of information**

Any information that is obtained in connection with this study and that can be identified to you will remain confidential and will be disclosed only with your permission, except as required by law. If you give us your permission by signing this document, we plan to discuss and publish the results at academic conferences and in academic journal publications. In any publication, information will be provided in such a way that you cannot be identified.

### **Recompense to participants**

We appreciate that it may be difficult and/or costly for you to attend our focus groups or interviews and participate in this project. To minimise this burden for participants, we are able to provide reimbursement of actual travel costs (\$70.00 per caregiver per focus group or interview) loss of wages or other expenses to those individuals who participate in our focus groups and interviews. There is some capacity for assistance with respite for the person you care for while participating in this study. Reimbursement will be made via cheque. You will need to include your postal details at the bottom of page 3 of this form.

### **Complaints**

Complaints may be directed to the Ethics Secretariat, The University of New South Wales, SYDNEY 2052 AUSTRALIA (phone 9385 4234, fax 9385 6648, email [ethics.sec@unsw.edu.au](mailto:ethics.sec@unsw.edu.au)). Any complaint you make will be investigated promptly and you will be informed of the outcome.

### **Feedback to participants**

The researchers would be happy to provide participants with any published material that emerges from this project. Please indicate whether you are interested in receiving such material on the attached consent form.

### **Your consent**

Your decision whether or not to participate will not prejudice your future relations with the University of New South Wales, HammondCare, Queensland University of Technology, the Consumer Dementia Research Network and the Dementia Collaborative Research Centres. If you decide to participate, you are free to withdraw your consent and to discontinue participation at any time without prejudice.

If you have any questions, please feel free to ask us. If you have any additional questions later, Associate Professor Chris Poulos (02) 8788 3900 will be happy to answer them.

You will be given a copy of this form to keep.



**PARTICIPANT INFORMATION STATEMENT AND CONSENT FORM (Continued)**

The University of New South Wales (School of Public Health and Community Medicine), HammondCare, Queensland University of Technology, the Consumer Dementia Research Network and the Dementia Collaborative Research Centres are undertaking this project entitled:

**“Beyond respite: designing effective wellness programs for carers”**

**You are making a decision whether or not to participate. Your signature indicates that, having read the information provided above, you have decided to participate.**

.....  
Signature of Research Participant

.....  
Signature of Witness

.....  
(Please PRINT name)

.....  
(Please PRINT name)

.....  
Date

.....  
Nature of Witness

Yes, I would like to receive any published material to emerge from this project

Please email me at this address: \_\_\_\_\_

Or mail to this address: \_\_\_\_\_

Postal address for reimbursement: \_\_\_\_\_



## Revocation of Consent Form

The University of New South Wales (School of Public Health and Community Medicine), HammondCare, Queensland University of Technology, the Consumer Dementia Research Network and the Dementia Collaborative Research Centres are undertaking this project entitled: **“Beyond respite: designing effective wellness programs for carers”**

I hereby wish to **WITHDRAW** my consent to participate in the research proposal described above and understand that such withdrawal **WILL NOT** jeopardise any treatment or my relationship with the University of New South Wales, HammondCare, Queensland University of Technology, the Consumer Dementia Research Network and the Dementia Collaborative Research Centres.

.....  
Signature

.....  
Date

.....  
Please PRINT Name

The section for Revocation of Consent should be forwarded to: Associate Professor Christopher Poulos, HammondCare Clinical Training Centre, 9 Judd Avenue, Hammondville NSW 2170.