



**The C.A.R.E. Tool:  
Examining the Role of Caregiver Assessment in Health  
Promotion of Older Spousal Caregivers**

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**Prepared by:**

**Pamela Fancey<sup>1</sup>, Janice Keefe<sup>1</sup>, Nancy Guberman<sup>2</sup> and Lucy Barylak<sup>3</sup>**

<sup>1</sup>Nova Scotia Centre on Aging, Mount Saint Vincent University

<sup>2</sup>École de Travail social, Université du Québec à Montréal

<sup>3</sup>CSSS Cavendish

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## 1. Introduction

Family and friend caregivers are the backbone of Canada's health and social service system. Study after study has demonstrated that care for disabled people in our communities is mainly care by family and friends (Cranswick, 2003; Cranswick & Perrier, 1999; Decima Research, 2002; Hebert et al., 1997; Keating, Fast & Frederick, 1999; Keefe, Hawkins & Fancey, 2006). Similarly, these same studies have documented the consequences of care responsibilities on caregivers' physical and mental health, social activities, personal finances, employment participation and relationships. Despite these data, there has been little change in policy and practice particularly with respect to assessing and addressing the needs of caregivers apart from their care recipient.

This discussion paper focuses on the caregiving experience of older spouses as caregiving demands for this population may be different and particularly burdensome if relief is not available (Stobert & Cranswick, 2004). Spouses may go to extreme lengths to keep their partner in the marital home (Miller, 1990) as the marital union is often the primary way in which an individual is defined. Affection and intimacy, mixed with espoused duty and obligation, are additional considerations in this caregiving relationship. Consequently, intense/long term caregiving responsibilities may place some senior spouses at risk. Spousal caregivers where dementia exists, in particular, are in an especially vulnerable position because they not only experience the loss of a life partner but also the loss of their own identity and self definition (Greenberg, Stacy & Penzo, 2001).

In addition to reviewing the literature on older spousal caregivers, the paper examines the strengths and limitations of the C.A.R.E. Tool in promoting and maintaining the health and well being of older spousal caregivers. The C.A.R.E. Tool is a psycho-social assessment instrument designed by the authors for use by home-care practitioners<sup>1</sup>,

Specifically, the objectives of this paper are:

1. To research and review the literature on caregiver assessment and its relationship to health promotion.
2. To examine the literature with an emphasis on the role of assessment in maintaining the health and well being of older spousal caregivers.
3. To review existing data of C.A.R.E. Tool assessments to understand in what ways the Tool may promote spousal caregiver health and well being.

The results presented in this paper are based on a systematic search of academic and non academic sources (see Appendix A for database and key words) as well as draw on the authors' expertise in the areas of caregivers and caregiver assessment. As well, the assessment data presented for older spousal caregivers are drawn from a recent Canadian study conducted by the authors, *From Policy to Practice: Assessing*

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<sup>1</sup> Guberman, N., Keefe, J., Fancey, P., Nahmiash, D. & Barylak, L. (2001). *The C.A.R.E. Tool. An Assessment of Caregivers' Aspirations, Realities and Expectations.*

*Caregivers of Persons with Alzheimer's Disease*, funded by the (US) Alzheimer's Association (2003-2006)<sup>2</sup>.

As previously stated, the overall goal of this paper is to discuss the C.A.R.E. Tool as a health promotion initiative for older spousal caregivers. To this end, the paper first presents results of the literature search on older spousal caregivers. A profile of this caregiving population is provided as well as what is known and documented with respect to the impacts on their health and well being. Particular attention is given to identifying the differences between older women caregiving spouses and older men caregiving spouses. Next, the rationale for assessing caregivers' needs as this practice relates to the promotion of health and well being is presented. Emphasis will be applied to the specific needs and circumstances of older spouses. An overview and introduction to the C.A.R.E. Tool as a health promotion initiative follows, outlining the breadth and depth of the instrument. Following this, data from assessments with older spouses using the C.A.R.E. Tool are presented. Finally, suggestions and recommendations for advancing caregiver assessment are offered.

## **2. The caregiving experience of older spouses**

Generally, the presence of a partner in later life offers a buffer against depression and poor health because there is someone to count on, give advice, make them feel loved and to confide in (Crompton & Kemeny, 1999). However, when a spouse's health status comes into play (and perhaps the resulting need for caregiving), marital relations may change despite the fact that caregivers often view their role as an intrinsic responsibility to their family or spouse/partner, or because they feel it is something, they want to do (Miller, 1990; Williamson, Shaffer & Schulz, 1998). Specifically, for spouses who vowed 'in sickness or in health' the sense of responsibility may be intensified. As well, the actual caregiving experience for women and men spouses may differ due to previous marital roles and responsibilities, emotional attachment, individual coping strategies, support network, age, health status of caregiver, spouse's diagnosis, etc. This section examines the literature on the caregiving experience of older spouses.

### *2.1 Prevalence of caregiving by older spouses*

Most studies on caregiving identify a range of family and friends who provide this valuable service to our community-dwelling older population. These relations include spouses, adult children, siblings, other family, friends and sometimes neighbors. Consistently, they all identify that the primary provider of care is women – wives, daughters, daughters in law, sisters, etc. Spouses make up the majority of caregivers to people who are married (Allen, Goldscheider & Ciambone, 1999) and compared to non spouse caregivers, spouses provide the most consistent and dependable care (Miller, 1990). Despite this significant contribution to the health system, no national studies have focused specifically on older caregiving spouses.

Isolating the prevalence of caregiving by older spouses within most existing studies is not an easy endeavour. Studies vary in their specific reporting of the proportion of

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<sup>2</sup> Approval was obtained from Mount Saint Vincent University's Ethics Review Board to conduct a secondary analysis of this project's data for this contract.

caregivers who are spouses, especially those 65 and older. This is largely due to differences in study design, scope of sample and variations in the definition of caregiving. In 1996 General Social Survey, caregiving is defined as someone over the age of 15 who provided assistance with at least one of several tasks in the past 12 months because of that individual's long-term health problem or temporary difficult time. This same definition is used in the 2002 General Social Survey which however was limited to Canadians 45 years of age and older providing assistance to someone 65 years and older. These definitions are broad including recent but not necessarily current situations, as well as situations that include non family and help given as a volunteer. A national study conducted by Health Canada adopted a more stringent definition. Included here were adult Canadians 18 years of age and older who were currently providing care to family member who is suffering form a physical or mental disability, is chronically ill or frail.

Data from the 1996 General Social Survey indicate that 5% of Canada's caregivers to the elderly were spouses. In this study, more than half of caregivers to the elderly were adult children (55%) (Keating, Fast, Frederick, Cranswick & Perrier, 1999). Most recently, data from the 2002 General Social Survey report that one quarter (25%) of Canadian caregivers 65 or older are providing care to a spouse (Stobert & Cranswick, 2004). The majority of them are women. Otherwise, a study commissioned by Health Canada in 2002 of adult Canadians providing care to a family member only reports that 77% of family caregivers are women. The proportion of older spousal caregivers in this study is not specifically identified but the study reports that 25% of adult Canadian family caregivers are 65 or older and suggests that, "Predictably, caregivers 35-64 years of age are most likely to be caring for a parent, while those 65 and older tend to be looking after a spouse or partner." (Decima Research, 2002, p.9).

## *2.2 What caregiving spouses are doing*

Caregiving spouses, compared to non spouse caregivers, resist institutional placement of the care recipient for a longer period of time despite level of disability (Miller, 1990), and, as a result, may take on many different roles in order to maintain their partnership and stay together in their home. While there is some suggestion that spousal caregivers provided a greater level of care to their partners than do other family members (Greenberg et al., 2001), it is difficult to isolate the extent of spousal caregiving responsibilities based on existing national studies. Results from the 2002 General Social Survey suggest that women caregivers 65 or older devote more time to caregiving activities than their male counterparts, and that senior women dedicate most of their time to household tasks and personal care – but these findings are not provided by care recipient (e.g., spouse, close friend, neighbor) (Stobert & Cranswick, 2004). Similarly, the Decima study (2002) does not report on caregiving tasks performed by type of relation but by gender. The traditional gendered division of tasks is confirmed – women more likely to provide assistance with basic activities of daily living (e.g., bathing, dressing, toileting), while men caregivers more involved in instrumental activities of daily (e.g., transportation, banking). Not specific to older spousal caregivers, one study examining gender differences in spousal caregiving in a sample of married people with cancer found that wives tended to be sole caregivers, while husbands who helped were more likely to have helpers. There were no statistically significant differences in the proportion of husbands and wives who helped with spouses with personal care needs; but husbands were less likely to help their sick spouses with household tasks (Allen,

1994). While age was a variable, it did not emerge suggesting these gendered roles continue into later life.

### 2.3 *Spousal caregiving and health and well being*

The experience of caregiving can be influenced by a host of factors. For caregivers generally they can include: geographic proximity, personal health, diagnosis, emotional closeness, age, employment status, geography, cultural/ethnic background, etc. For spousal caregivers, the experience can be intensified by the status of their own personal health, access to supports (e.g., other family, formal services), diagnosis of partner (e.g., physical frailty, incontinence, and dementia), gender and age (younger senior compared to older senior). For example, when dementia is present a sense of loneliness, resentment or aggravation may be felt by the caregiving spouse as their partner may no longer be able to communicate the way they once did (Adkins, 1999; Beeson, 2003; Gallant & Connell, 1997; Siriopoulous, Brown & Wright, 1999) or participate in intimate/sexual relations (Davies, Zeiss, Shea & Tinklenberg, 1998; Svetlik, Dooley, Weiner, Williamson & Walters, 2005). Further, because gender role norms play out in spousal caregiving (Allen, Goldscheiber & Diambro, 1999; Miller, 1990; Mui, 1995), generalizations of women spousal caregiving experiences are problematic as men spouses may be placed in unfamiliar roles.

Existing studies specifically on spousal caregiving offer many insights into the impact of caregiving responsibilities on one's health. While the majority focus on negative consequences, a few studies illustrate the benefits of helping a spouse to one's health. Beach, Schulz and Yee (2000) found that increases in the help provided were related to better mental health (i.e. decreased anxiety and depression). Another study examining the costs and rewards of caregiving among aging spouses and adult children found that while adult children experience more rewards generally than spousal caregivers, in situations where the spousal care recipient was helpful caregiving spouses were particularly appreciative thereby buffering some of the noted caregiver costs (Raschick & Ingersoll-Dayton, 2004). In other studies, respondents discuss the notion of reciprocity or giving back as being a reward of their caregiving (Russell, 2001; Siriopoulous et al., 1999).

Otherwise, caregiving for a disabled elderly spouse has implications on physical health, mental health and health risk behaviours. Poor physical health may increase the risk of depressive symptoms in caregivers (O'Rourke, Cappeliez & Guindon, 2003 cited in Mittelman, Roth, Clay & Haley, 2007) and the relationship between caregiving and poor physical health is especially strong among older caregivers, dementia caregivers and spouse caregivers (Pinquart & Sorensen, 2003). Beach, Schulz, Yee and Jackson (2000) in a comparison of caregiving spouses and non caregiving spouses report increases in felt caregiver strain by caregiving spouses (e.g., emotional and physical) were consistently predictive of poorer perceived health, increases in health-risk behaviours (e.g., poor eating, lack of exercise, general rest, rest when sick, inconsistent medications, reduced attention by health professionals) and increase in anxiety and depression. Changes in caregiver's health behaviour and health status are also noted by McConnell (1994) in a study of spousal caregivers of dementia. Over one-third reported they ate less nutritiously and reduced their level of physical activity. A smaller proportion increased smoking and alcohol consumption. Forty percent reported their physical health had been negatively affected citing tiredness, stress, sleep disturbances, weight gain, etc. Similarly, Gallant and Connell (1994) noted several health behavioral changes since

caregiving amongst a sample of older spousal caregivers of a partner diagnosed with dementia. Caregivers experienced weight fluctuations, reduced physical activity and poorer sleep habits (e.g., reduced sleep and interrupted sleep). However, very few caregivers reported an increase in drinking or smoking.

Mui (1995) studying the impacts of caregiving on spousal caregivers' perceived health status and ability to perform ADL and IADL found that wife caregivers had poorer health despite husband caregivers being, on average, older. Predictors of wives' poor health included emotional strain, unmet needs of the care recipient, depression of care recipients, while for husbands predictors included emotional strain, caregiving duration and perceived role conflict in personal and social life. There were no gender differences on self-reported functional status. Emotional strain was a common predictor of reduced functional status for both men and women caregivers. Otherwise, for wives, care recipients perceived unmet needs was a significant predictor and for husbands, care recipient functional impairments and caregiving duration were associated with poor their own poor functional status. These results suggest that the care recipient's health status is a key factor in the experience of caregiving spouse and resulting impacts on health. For example, Beach and colleagues (2002) found that changes in spouse physical impairment levels were related to poorer health-related outcomes, specifically, increased impairment was related to increased health risk behaviours (see above) and anxiety. In another study comparing caregiving spouses of persons with Alzheimer Disease (AD) and non caregiving spouses, the presence of dementia is important. Beeson (2003) found that AD caregivers, compared to non caregiving spouses, reported significantly greater loneliness and depression. As well, AD caregiving wives report a greater loss of self and significantly higher levels of loneliness and depression than did AD caregiving husbands. Mui's (1995) sample of spousal caregivers involved 92% of care recipients having moderate to extreme severe impairments and half of all care recipients experienced incontinence problems. Similarly, a study examining the impact of caring for a spouse experiencing incontinence (Cassells & Watt, 2003) found that caregivers reported a wide variety of consequences. These included: role change, financial cost, social isolation, sleeping issues, decreased intimacy and emotional responses.

The link between changes in care recipient's impairment and caregiver's ability to engage in social activities should not be overlooked in this discussion. Spousal caregivers who encounter a decrease in social activity and social networking often experience social isolation (Kramer, 1997; Mui, 1995) which in turn can intensify stress and burden and enhance symptoms of depression. Draper, Poulos, Poulos and Ehrlich (1995) found higher levels of burden amongst older caregivers who reported a worsening in their relationship; poor perceived health status, shorter length of caregiving, caring for a more physically disabled person, caring for a person with mood/behaviour disturbance. They also note that caregiver stress was attributed to lower levels of social activity and increased social isolation because of caregiving demands. Social isolation and psychological distress was also present in a study of older male caregivers of wives with dementia (Kramer, 1997). These men stated they had lost much of their social interaction throughout the progression of their caregiving role and indicated a desire to speak with other men in similar situations. This type of social isolation, not being able to communicate with people who have similar problems or going through comparable circumstances, can have negative impacts on the caregiver as social activities are an important part of maintaining one's psychological and psychosocial well-being (Kramer, 1997). Social support can function as a buffer for social isolation for spouse caregivers of persons with dementia but gender differences may exist (Miller & Guo, 2000; Russell,

2001; Siriopoulous et al., 1999). Male caregivers are more likely to receive emotional support from adult children and to receive practical assistance from formal sources compared to wife caregivers (Miller & Guo, 2000).

Embedded in the discussion so far has been the recognition of gender differences in the experience of older spousal caregiving. However, male caregivers are noticeably neglected by researchers (Canadian Caregiver Coalition, 2003), and male spouses in particular. This is the case despite literature that suggests that men may approach caregiving responsibilities in a more instrumental and objective way helping to insulate them from some of the emotional stresses and burden commonly reported by women (Applegate & Kaye, 1993). As well, because women are more likely than men to develop Alzheimer's Disease, men may be disproportionately caring for spouses with dementia (Applegate & Kaye, 1993). While studies usually include women and men caregivers, more specific attention should be given to men as the majority of spousal caregivers are women and generalizations to men from these studies may be problematic.

A few studies focusing specifically on older husband caregivers of wives with dementia lend support to husband caregivers assuming more of a management role (Russell, 2001; Siriopoulous, Brown & Wright, 1999), employing a proactive coping strategy (Kramer, 1997) and seeking and accepting assistance from family and formal services (Russell, 2001; Siriopoulous, Brown & Write, 1999). At the same time, older male caregivers may be more at risk of social isolation because of their spouse's role in maintaining social relations over the years (Russell, 2001; Siriopoulous, Brown & Wright, 1999) and caregivers' inability to engage in the same level of leisure activities because of the increasing responsibilities associated with the dementia (Kramer, 1997; Shanks-McElroy & Strobino, 2001). With respect to their personal health, husband caregivers who were dissatisfied with their participation in leisure activities reported poorer health (Kramer, 1997; Shanks-McElroy & Strobino, 2001) lending support to the importance of not just taking time off from the situation but taking time to maintain their health and well being (Shanks-McElroy & Strobino, 2001). Another contributing factor to caregiver's compromised health included the challenges associated with providing personal care and managing behavioral outbursts associated with the disease (Kramer, 1997; Shanks-McElroy & Strobino, 2001). While these male-focused studies make a valuable contribution, their results should be used with caution due to their small sample sizes and study design.

Like gender, dementia emerges as a dominant theme in the caregiving literature. Caregiving for someone with a dementia has been associated with clinical depression (Beach et al., 2000; Covinsky et al., 2003; Davies et al., 1998; Dura, Stukenberg & Giecolt-Galser, 1990; Redinbaugh, MacCallum & Kiecolt-Glaser, 1995<sup>3</sup>), behaviour /mood disturbances are risk factors for burden and psychological morbidity among elderly caregivers (Draper et al., 1995), and chronic stress such as experienced in caring for a progressively dementing spouse has been linked to poor cognitive performances in older adult spousal caregivers (Caswell et al., 2003). Studies vary in terms of the factors contributing to depression in dementia cases. They include demographic characteristics (see Covinsky et al., 2003), loneliness (Beeson, 2003) and dysfunctional/disruptive behaviours (Donaldson, Tarrier & Burns, 1997; Schulz, O'Brien, Bookwala & Fleissner,

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<sup>3</sup> See also Adkins, V. (1999). Treatment of depressive disorders of spousal caregivers of persons with Alzheimer's disease: A review. *American Journal of Alzheimers Disease and Other Dementias*, 14(5), 289-293.



1995; Russo, Vitaliano, Brewer, Katon & Becker, 1995 cited in Beeson, 2003). There is also some evidence that women and spousal caregivers are at higher risk for depression (Beeson, 2003; Donaldson et al., 1997; Dura et al., 1990; Schulz et al., 1995). The relationship between dementia and caregiver depression is one not to be disregarded by health professionals because of its link to poor quality of life and consequences such as functional decline and mortality (Covinsky et al., 2003).

#### *2.4 Caregiving and health promotion*

Caregiving is an emerging public health issue which requires attention by decision makers and health officials. Changing demographics (e.g., increase life expectancy, increased participation of women in the labour force), concerted efforts to manage health care resources and delay institutionalization are all contributing factors to this growing public health concern. Caregiving not only has the potential to affect the individual's health and well being but also that of the care recipient, their family, their communities and the health care system in general. The better the health of the caregiver, the more likely the quality of life for the care recipient is high, and there is less demand on acute health care resources. As previously discussed, with increasing caregiving responsibilities caregivers often find it difficult to take time for themselves, yet the concept of individuals attaining healthy lifestyles is formed when one is able to concentrate upon their unique health needs. These needs can encompass one's psychological, physical, spiritual, and emotional well-being (Acton, 2002; Bond, Clark & Davies, 2003; Mui, 1995b; Raschick & Ingersoll-Dayton, 2004). As caregiving responsibilities increase caregivers have reduced time to maintain their engagement in recreational and social activities (e.g., friends and family), reduced time for volunteer or community work, eating nutritiously and sleeping well. Further, feelings of psychological distress which often accompany caregiving can result in changes in health-related behaviour such as increased smoking and alcohol consumption, forgetting to take their own medications and neglecting to seek health care when necessary. Moreover, older spousal caregivers may be particularly vulnerable because of their advancing age and increased prevalence of chronic illness, potentially reduced physical capacities (McConnell, 1994) and general reluctance to seek help.

While it is often difficult to disentangle the cause and effect, caregiving and changes in health are inter-connected. Understanding caregiver's situations (e.g., their experiences, expectations, needs) and identifying/monitoring changes in their health and well being are key to effective health promotion activity.

Self-efficacy can also play a key role in the health promotion of a caregiver's life as it does not decline as one ages. Caregivers who believe their self-efficacy is great are more likely to feel in control of their situations and circumstances, thus having vast effects on their health and well-being. In a study, Grembowski and colleagues (1993) found that a caregiver's self-efficacy only had a positive impact on their health when the care receiver's efficacy was lower than theirs. The study went on to state that health promotion should not necessarily be focused on improving one's self-efficacy but rather on how to make positive changes to behaviors and how to support this. To this end, caregiver assessment, implementing and monitoring a care plan for the caregiver is key.

## 2.5 *Issues with the literature on older spousal caregivers*

Sections 2.1 to 2.4 raise several issues to be considered when discussing the health and well being of older caregiving spouses. First, within the existing Canadian studies there is little specific information on older spousal caregivers. This includes information on prevalence, who they are, and what they do. A compounding factor with this issue may be the recognition that spouses do not self-identify as “caregivers” but rather as continuing on with expected spousal responsibilities. This can influence sample recruitment and, as a consequence, study results. Further, because studies do not always isolate this population, assumptions are being made about who does what and this presents challenges when reviewing the literature with respect to understanding impact of caregiving. Likewise, the studies cited previously do not specify the range of caregivers ages or include a broad range of ages despite their focus on *older* spouses. For example, Gallant and Connell (1997) include men whose average is 70 years and women whose average age is 66 years while Beeson (2003) reports caregivers’ average age as 74 years and the average age of the comparative, non caregiving, group as 78 years. Other studies include caregivers whose age ranges from 51 to 86 (Kramer, 1997), 59 to 88 years (Shanks-McElroy & Strobino, 2001) or 68 to 90 years (Russell, 2001). Often the reference point or study question is about care of the older impaired or frail spouse so age of the caregiver is not necessarily a criterion to determine eligibility. Because of the relationship between increasing age and increasing limitations due to health, the inconsistent approach to identifying older caregiving spouses makes comparative analysis difficult. Finally, while many studies include gender as a variable the majority of spousal caregivers are women. Generalizations to older spousal caregiving men are problematic. Likewise, caregiving situations where dementia is present constitute a large portion of the literature. Generalizations to other illness/frailties are problematic.

## **3. What we know about caregiver assessment and its relationship to health promotion**

The World Health Organization contends that “Health promotion is the process of enabling people to increase control over, and to improve, their health.” This may include education and environmental supports conducive to promoting positive health and reducing risks focused on macro-level systems as well as individual circumstances. Notions of healthy aging and age-friendly communities come into play here as well. Recent work on what makes rural and remote communities age friendly identifies caregiver support an essential ingredient (Federal/Provincial/Territorial Ministers Responsible for Seniors, n.d.). Likewise, models of health and successful aging not only include disease prevention but also recognize the importance of opportunities to engage in life and the ability to maintain cognitive and physical functioning (Marshall & Altpeter, 2005).

Caregiver assessment fits well in the discussion of health promotion because it provides evidence which can contribute to macro-level systems by helping the health system to better understand caregivers who are particularly vulnerable for burnout and to then design and implement interventions to address caregivers’ needs (Talley & Crews, 2007). From the health care perspective, caregiver assessment provides the conditions for professionals to obtain information on the global care situation needed to build

individual and collective supports for caregivers. At the individual level it is a process enabling people to increase control over and improve, their health by better understanding the challenges and opportunities as well as the resources and supports that caregivers need to maintain their health and well being. It opens the doors for caregivers to health and social resources they may not have previously had access to. Caregiver assessment also be therapeutic and enhance self-efficacy by providing an opportunity to tell their story, analyze their individual needs, take time from their everyday experience to self-assess their strengths and limitations, and receive recognition that their contribution is important.

With respect to prevention and health promotion, a better understanding of the caregiver's circumstances, worries and difficulties helps to better assess risks to their well being and to the caregiving situation (Audit Commission, 2004; Pickard, 2004), to reduce burden (New Zealand Guidelines Group, 2003) and to counter the negative consequences of caregiving (Gaugler, Kane & Langlois, 2000). This understanding recognizes that caregivers' needs may differ from those of the care receiver, thus helping them plan support services accordingly (Feinberg, 2004). Moreover, most of the health-related research on family caregiving has focused on the health problems exacerbated by caregiving duties. Much of this work has focused on a stress-illness framework. Acton (2002) suggests that attention should be given to health-related variables within a health-promotion model. Such areas to include perceived importance of health promotion, barriers to health promotion, self-efficacy for health promotion, health responsibility, physical activity, nutrition, spiritual growth, interpersonal relations, stress management, etc. Caregiver assessment provides a valuable opportunity to uncover the factors/conditions influencing health promoting behaviour and practices and develop a plan to help address them.

The outcomes of caregiver assessment, namely intervening prior to caregivers reaching burnout or a crisis point, provide the ultimate reason for considering assessment as a health promotion initiative. The few experiences where assessment has been implemented and evaluated point to extremely positive outcomes for all involved: caregivers, care receivers, practitioners and agencies, and provide strong motives for implementing caregiver assessment.

#### *Outcomes for the caregivers*

A limited number of studies evaluating the experiences in the UK and Australia, including both mandated assessment and pilot research projects, point to the following outcomes for caregivers: recognition of their role; a chance to talk through their issues and consider their own needs; self-understanding of their situation, feelings and the caring role; new insights into why they are caring and what they have achieved; expression of bottled-up emotions; permission to talk about difficult and delicate subjects; validation of their feelings; acceptance of support; peace of mind in knowing how to make contact in the future; information and referral information; a sense of shared responsibility; increased confidence to take up services; confirmation as people of value; recognition and validation (Carers UK, 2002; Hepworth, 2003; Lundh & Nolan, 2003; Maddock, Kilner & Isam, 1998). Studies have documented the therapeutic impact of caregiver assessment (Lundh & Nolan, 2003) that recognizes and validates them and offers an opportunity to have their situation taken seriously. Documented positive impacts of caregiver research-based intervention in the U.S. point to the importance of providing the appropriate service at the appropriate time, based on comprehensive assessment (Gitlin, Hauck, Dennis & Winter, 2005; Hoskins, Coleman & Neely, 2005; Mittelman, Roth, Coon & Haley, 2004). This in turn prevents premature placement of the person requiring care in a facility.

In their carer needs assessment trial, Maddock and colleagues (1998) found that one month after assessment, of the 51 caregivers involved, 67% stated they were more able to continue in their role because of the assistance/support provided by nurses after assessment, 58% had higher perceived levels of social support, 46% had decreased information needs and 50% had decreased levels of strain. A pilot project in Maine appears to show that when caregivers are screened by primary health professionals and referred to AAA caregiver services they have increased knowledge levels and decreased levels of depression at six months after initiation of services, despite increased task frequency and difficulty (Kaye et al., 2003).

#### *Outcomes for care receivers*

There is little research on the impact of caregiver assessment on the care receiver, but subjective appreciations from practitioners indicates that if caregivers' well-being is enhanced this has positive repercussions for the care receiver and there is some research data which supports this (Maddock et al., 1998).

#### *Outcomes for practitioners*

Evaluations of the impact of caregiver assessment on practitioners tend to agree on the following: assessments raise awareness of caregiving situations and provide insights and increased understanding of what it means to be a caregiver and of the daily realities of care; enhance understanding of the complexities of caregiving; challenge existing perceptions/expectations; change taken-for-granted assumptions; enable a better response to caregiver needs; enable going beyond symptoms to understanding the underlying causes of caregiver difficulties; release innate creativity (Guberman et al., 2001; Lundh & Nolan, 2003; Maddock et al., 1998; Nicholas, 2003).

Caregiver assessment is a health promotion/preventive initiative as it aims to intervene prior to caregivers' reaching burnout or a crisis point. Yet despite the evidence that demonstrates the positive impact of caregiver assessment on caregivers' health and well being (Carers UK, 2002; Hepworth, 2003; Lundh & Nolan, 2003; Maddock et al., 1998) and the many studies that call for caregiver assessment to help health care professionals be better equipped to support caregivers (AARP, 2006; Barylak, Guberman, Fancey & Keefe 2006; Barylak, Silverman & Orzeck, 2007; Bull & McShane, 2002; Cousins, Davies, Turnbull & Playfer, 2002; Covinsky et al., 2003; Feinberg, 2004; Levine, 2006; Sorensen, Pinquart & Duberstein, 2002; Talley & Crewes, 2007), to date there is little concerted effort to implement a comprehensive caregiver assessment into healthcare practice throughout Canada (Barylak, Silverman & Orzeck, 2007). Particularly for older caregiving spouses who will may be caregiving for extended lengths of time and endure great strain to keep their partner at home, without a comprehensive assessment and intervention plans the caregiver's health is being jeopardized and potentially the health of their ailing partner as well.

#### **4. The C.A.R.E. Tool as a health promotion strategy**

In 2001, with support from Health Canada, the authors developed and undertook a process to validate a psycho-social assessment tool for caregivers (Guberman et al., 2001). This assessment is multi-dimensional in scope providing a health care

professional the opportunity to obtain an in depth understanding of the issues discussed in section 2.3 and the opportunity for the caregiver to feel validated.

During the assessment, what the caregiver is doing and the difficulties s/he may have with those tasks are discussed (section 2). This caregiving work section covers physical/nursing care, household work, support/supervision, and coordination of outside supports/services. From these questions, the health care professional will start to understand factors that are impacting the individual's physical and emotional health. The assessor also discusses with the caregiver the extent and usefulness of support from others; these questions can often help to identify services currently in place that are ineffective and the reasons or relations with family members that may be stressful. Section 3 is dedicated to understanding relations with health care professionals as interacting with primary health care providers is an important role of the caregiver. Section 5 helps to identify what other activities and responsibilities the caregiver may have but is unable to fulfill. These activities, such as participating in one's church or other volunteer activities, engaging in leisure/recreational activities, or helping with child care may offer the caregiver opportunities for important respite<sup>4</sup> but if unable to participate in these commitments because of their caring role this restriction, as previously discussed, can contribute to increased feelings of strain and even depression. This again can help to identify potential stressors on the caregiver's emotional health.

Many of the sections contribute to understanding impact on the caregiver's health and well being, but Section 7 is solely dedicated to understanding caregiver's personal health – both physical and emotional. Here, health care professionals understand the general state of the caregiver's health and, in particular, changes in a range of health behaviours since the individual became involved in caregiving (e.g., sleeping, nutrition, health care, alcohol consumption, weight, sexual life) and changes in a range of feelings (e.g., boredom, exhaustion, sadness, guilt, loneliness, anger, depression). The health care practitioner also discusses with the caregiver the coping strategies s/he currently uses and whether further support is needed.

Section 8 focuses on relationships. It not only identifies with whom the caregiver may be experiencing changes or conflicts (e.g., care receiver-partner, other family) but also identifies the areas of tension and contributing factors to the change in relations. This can include certain behaviours of the care receiver if a dementia is present or in the case of relations with other family members, lack of support, expectations, or different perspectives on the care. Here, the caregiver is also asked to consider his/her personal strengths, what is rewarding about caregiving and whether they feel appreciated. These questions are particularly important in promoting self-efficacy. Section 8, at times, can be very sensitive but has been reported to be very beneficial in helping to identify individual strengths and capacities as well as pinpoint the specific cause of a lot of stressful caregiving situations.

Finally, remaining sections focus on planning for crises situations when the caregiver may be unavailable, planning for the future care needs of the individual and identifying the services that could help if they were available. This latter section is important to help identify the type and format of services that would be beneficial for caregivers.

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<sup>4</sup> Employment is also included in this section on Juggling Responsibilities, but this activity would be less relevant to older caregiving spouses.

The comprehensive profile of the caregiver, the specific difficulties that the individual is facing as well as the reason for these challenges are essential ingredients in developing informed care plans for the caregiver. Where caregiver assessment is linked to care plans and the provision of services, the C.A.R.E. Tool has great potential to influence caregivers' health and well being. In other ways, the assessment can contribute to increased feelings of worth and value because the health care professional has dedicated specific time for them, and the results of the assessment can also inform program and policy development to support caregiver health and well being on a larger scale.

## 5. The C.A.R.E. Tool and older caregiving spouses

A recent study completed by the authors informs this section. A sub-sample of 99 caregiving spouses 65 years of age and older is selected from the project, *From Policy to Practice: Assessing Caregivers of Persons with Alzheimer's Disease* (2003-2006; funded by Alzheimer's Association, US). This project's quasi-experimental design was intended to assess the impact of implementation of the C.A.R.E. Tool in publicly funded home care programs on caregivers of persons with and without Alzheimer's disease and service organization. All caregivers participated in an interview at the start and conclusion of the project. The C.A.R.E. Tool was administered to approximately half of the caregivers in the study by practitioners working in home care agencies in Quebec (5 agencies), Prince Edward Island (4 regions) as well as Veterans' Affairs Canada (4 offices).

The older caregiving spouses are mostly wives (80%). On average, these spouses are 75 years of age (s.d.=5.770; R=65-89 years) and, on average, have been caregiving to their partner for more than 5 years. Less than half of the caregiving situations (43%) involve dementia yet nearly all (97%) provide care either "daily" or "all the time". This suggests that in cases where dementia is present or not the needs of the partners are heavy.

In terms of personal health, at the beginning of the project these older caregiving spouses on average scored 72 (out of a possible 115) for caregiver well being (part a – fulfillment of activities of daily living<sup>5</sup>) and on average scored 78 (out of a possible 110) for caregiver well being (part b – fulfillment of basic needs<sup>6</sup>)<sup>7</sup>. More than half (58%) perceived their own health to be "average" or "poor".

As mentioned previously approximately half of caregivers participated in an assessment with a home care practitioner using the C.A.R.E. Tool. This assessment was to be completed within a month of the first interview. Of the 15 areas the instrument addresses, the main areas of difficulty identified for older caregiving spouses were planning both for crises and future care needs, household work, physical health and emotional health (see Table 1).

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<sup>5</sup> 23 items, higher score means higher well being

<sup>6</sup> 22 items, higher score means higher well being

<sup>7</sup> Tebb, S. (1995). An aid to empowerment: A Caregiver well-being scale. *Health and Social Work* 20(2), 87-92.

Table 1 – Assessment of areas of difficulty

Area	Level of difficulty			
	None	Little	Some	Significant/ Extreme
Physical Care	2%	68%	21%	9%
<b>Housework</b>	<b>2%</b>	<b>53%</b>	<b>32%</b>	<b>13%</b>
Supervision/support	4%	60%	23%	14%
Coordination	4%	79%	17%	0%
Help Received	2%	68%	21%	9%
Relationship with Formal Services	4%	87%	6%	4%
Housing	4%	77%	15%	4%
Juggling Responsibilities	4%	76%	15%	6%
Financial Costs	6%	77%	12%	6%
<b>Physical Health</b>	<b>2%</b>	<b>49%</b>	<b>36%</b>	<b>13%</b>
<b>Emotional Health</b>	<b>2%</b>	<b>45%</b>	<b>40%</b>	<b>13%</b>
Relationship with CR (partner)	2%	67%	21%	10%
Relationship with Family	4%	83%	10%	4%
<b>Crisis Planning</b>	<b>2%</b>	<b>56%</b>	<b>19%</b>	<b>23%</b>
<b>Future Planning</b>	<b>2%</b>	<b>46%</b>	<b>21%</b>	<b>31%</b>

From this rating exercise, practitioners are asked to identify the top three key areas of concern for the caregiver which help identify priority areas for services to be recommended. For example, if the caregiver was experiencing some of significant/extreme difficulty with housework, poor physical health is often identified as a key area of concern. The caregiving spouse due to age, their own health concern and the extent of household work being performed may have less physical reserve to complete such tasks resulting in increased strain and burden.

While planning is an area that requires attention, the most common “key areas of concern” identified for older caregiving spouses<sup>8</sup> include:

- the need for respite/time for self
- poor emotional health
- poor physical health.

These areas of concern speak directly to caregiver’s health. For these cases, the most commonly identified services recommended to address these concerns included respite, case management and homemaking/home support services. These concerns may have been ameliorated if these issues were identified earlier on in the caregiving process and appropriate supports put in place. Again, the majority of these older spousal caregivers have been in this role for more than five years and nearly all in heavy care situations,

<sup>8</sup> Gender analysis would be interesting, but this was unable to be performed due to low number of husband caregivers in the study.

due to dementia or physical frailty, so the strain on their personal health is well entrenched at this stage of the journey.

Generally, the results that examine whether having an assessment has a differential impact are not significant for these caregivers. Although, older caregiving spouses who received the assessment compared to those who did not were found to have, on average, greater negative change (less well being) (see Table 2) these differences were not statistically significant either between the two groups. This suggests that the negative change on caregiver well being for all caregivers is being driven by some factor other than receiving an assessment. One challenge with this analysis is that it is drawing on group averages over time of very individualized experiences and circumstances. What potentially are lost here are the situations in which the assessment may result in positive change or at least reduce the degree of negative change. This method limitation may be addressed by examining select cases in more depth below.

Table 2 – Differences on caregiver well being scores by whether assessment was received

	Received Assessment (average change in score)	No Assessment (average change in score)	
Caregiver well being – part a	-3.3116	-1.3627	$t=1.120$ , ns
Caregiver well being – part b	-2.7479	-2.1474	$t=.492$ , ns

When examining change in other aspects of the caregiving situation such as caregiver role, awareness/access to supports and recognition no significant differences emerge for those receiving the assessment compared to those who did not receive the assessment.<sup>9</sup> It is understandable why change does not occur for older caregiving spouses on some of the items included in the study. For example, a spouse/partner would likely always be very involved in decisions regarding services. Given that the majority of older caregiving spouses are women they would see themselves as having little choice in their involvement as a caregiver for their partner, unlike some other relation. And, given the length of caregiving time as well as level of care needs, these individuals would likely have been informed about their partner’s condition and existing services and support in their community. It should be noted that service providers being more aware of the caregiver’s role neared significance suggesting that the assessment had some part in this change.

Interestingly, from the practice perspective we understand that practitioners find the C.A.R.E. Tool useful, provides them with new information about the caregiving situation they did not have previous, helps them identify caregivers’ concerns and helps practitioners identify challenges with current services<sup>10</sup>. Given these messages, change

<sup>9</sup> This finding is different than for all caregivers in the study that finds change on select items between those receiving the assessment and those not.

<sup>10</sup> These comments from practitioners were for older caregiving spouses only and extracted from Section 13 of the version of the C.A.R.E. Tool used for this study. Section 13 was intended to capture feedback from the practitioner using the instrument in terms of its utility.



on a few of the items would be expected (i.e. service provider being more aware, change in service allocation, and greater recognition as a caregiver). With the exception of service providers being more aware this is not the case, according to the caregivers.

#### Scenario 1 – Henry and Gloria

*Henry is a 81 year old caregiver to his 75 year old wife, Gloria, who suffers from Chrones Disease, arthritis and recently had hip replacement surgery. His time in this role is relatively short, 2 months, but reports assisting Gloria on a daily basis. He helps with household work, accompanies Gloria to appointments and assists with mobility (particularly with stairs). He also receives support from their daughter. The local home care agency became involved at hospital discharge and during Gloria's immediate recuperation period, physiotherapy was provided. This put Henry in contact with the local home care agency and he then agreed to participate in an assessment. During the assessment, the home care practitioner learned that, generally, Henry is in good physical health despite having a heart condition and he continues to be able to engage in leisure activities. Because Gloria has some mobility problems he assists her with many of the household tasks, but he is not solely responsible for them so does not carry the full burden of these new responsibilities. There are no issues of supervision or support in this case. He scored high on both parts of the caregiver well being scale. However, Henry shared that sometimes he has feelings of sadness, depression and exhaustion. These feelings seem to be connected to his thinking about the future. In particular, he worries about the deterioration of his wife's health and its affect on care needs and the inaccessibility of their marital home should his wife's mobility not improve. As well, Henry reports some concerns about their finances. During the post interview, Henry commented that because he was in touch with the local home agency he is more aware of available services, and their cost, that may be necessary in the future. The practitioner also discussed with him the need for crises and future planning given the concerns about declining health needs, and he and his wife would be open to this discussion with a case manager should one be available to them through the local home care agency.*

This scenario is an example of where assessment in the early stages may help to better equip Henry and Gloria to face the increasing care needs that are likely pending for them. Henry has positive scores on the caregiver well being scale at the beginning and four months later, his well being scores increased. From the practitioner's perspective she was able to better understand his emotional concerns about the future and make helpful recommendations for him. For Henry, having access to a health care professional to discuss his concerns and making him more aware of services provided some ease.

#### Scenario 2 – Janet and Doug

*Janet is a 76 year old wife providing care for her 78 year old husband, Doug, for more than 10 years. Doug is an insulin-dependent diabetic whose mobility at times is limited. He requires assistance with personal care (e.g., dressing, grooming, bathing) and is incontinent. Janet provides care "all the time". She receives substantial assistance from a daughter who is a nurse and receives some respite. In addition, through the home care agency a nurse monitors the medications and they also receive some occupational therapy services. While Janet wants to continue care for her husband she is finding it increasingly difficult. In particular, areas of difficulty were identified as housework, supervision and support, physical and emotional health. Initially she reported her health*

*to be good but four months later as fair as she herself is undergoing diagnostic tests for health concerns. She is no longer sleeping well, she is experiencing backaches and headaches and her use of medications has increased. She reports feeling exhausted, overwhelmed, sadness, loss/grief and sometimes has feelings of discouragement, worry, helplessness and frustration. She has given up leisure activities and participating in social events with friends. The home care practitioner has known Janet and Doug for six years. From the worker's perspective it provided a new light on the struggles and challenges Janet was experiencing, especially the lack of respite services to give her a meaningful break from her caregiving responsibilities. For Janet, the assessment process provided her a valuable opportunity to talk about her issues with respect to Doug's care and helped her to feel more appreciated. During the assessment, discussions took place about future planning for increasing care needs and Janet is pursuing an application for long term placement. In the meantime, while this particular home care agency has limited resources an "enrichment" of existing services, namely respite, occurred.*

This scenario is an example of the assessment process providing a new and in depth perspective on an existing case. Doug's needs have been assessed over the years, but the focused attention to Janet, his caregiver has been missing. Likely due to increasing physical demands and emotional strain of Doug's care over the years, her own health has deteriorated to a point where she is unable to continue care despite her desire to do so. Had Janet participated in a comprehensive assessment earlier in the caregiving journey, access to additional resources and supports may have been introduced if the agency were able to do so. At the minimum, the caregiver would have an opportunity to express her concerns to a health care professional and her needs monitored. This process may have been therapeutic for her in view of the emotional strain she currently experiences and it could have been impressed upon her the importance of maintaining her leisure and social activities. In terms of change post assessment, Janet feels that after talking with the health care professional she now has more choice in the caregiving role (i.e. long term care placement), that the service provider is significantly more aware of her role and concerns and that there had been a change in service allocation (i.e. enrichment of existing respite service). Overall, her well being scores declined slightly for activities of daily living but increased in terms of fulfillment of her basic needs.

These two cases provide evidence of the value of implementing the C.A.R.E. Tool into practice, particularly as a primary way to identify needs and promote caregiver well being. Both cases offer a different and more insightful perspective on the importance of caregiver assessment than previously presented by the aggregated data.

## **6. Recommendations**

This paper demonstrates that caregiver assessment should be considered an important public health issue, especially for older Canadians who find themselves caring for their partner. Yet in most cases assessment has not been put into practice, leaving a large gap in service delivery and support to caregivers. Based on a review of existing literature and data from assessments with older caregiving spouses, the following recommendations for policy, practice, and further research are offered.

- Awareness of this issue is required to evoke action. It is recommended that the Public Health Agency of Canada promote caregiver assessment as a health promotion initiative helping to build the case for provincial and territorial bodies to implement caregiver assessment into practice.
- Comprehensive caregiver assessment practices, such as possible with the C.A.R.E. Tool, are required if caregivers' health and well being are to be maintained and sustained. It is recommended that home care agencies implement caregiver assessment into their practice, with the goal of assessing early in the caregiving journey to identify and monitor specific and changing needs.
- Caregiver assessment is the first step and should be complemented with services to address the needs that emerge. It is recommended that where assessment is implemented into practice, public resources be made available to develop services and supports responsive to caregivers' needs. Alternatively, evidence from the assessment process is made publicly available to mobilize other stakeholders to develop and offer necessary services.
- Education of health care professionals about caregivers is important. It is recommended that caregiver assessment be integrated into education programs of health care professionals so they are trained to keep caregivers in mind throughout their practice. As well, it is recommended that front-line workers in various care settings, including primary care, participate in continuing education sessions intended to sensitize them to caregiver issues and the importance of health promotion and prevention.
- Issues exist with current information about the prevalence and roles of older spousal caregivers and the impact of caregiving on their health and well being. It is recommended that national research specifically on older spousal caregivers, with a strong representation of husband caregivers, be undertaken to fill the knowledge gap on this population.
- Methodological challenges limit the utility of existing data available from the authors' C.A.R.E. Tool project, yet evidence is needed to support decision making. It is recommended that further research be funded to assess the more immediate impact of the C.A.R.E. Tool on caregivers' health and well being (i.e. apply post assessment measure within a few days as opposed to 3-4 months).
- Older caregivers are expected to increase in numbers. It is recommended that this focussed examination be extended to other older, non spousal, caregivers such as siblings, friends and even adult children. Given that life expectancy is increasing more Canadians 65 years and older may be caring for their 90 year old parents.

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## **Appendix A**

### Literature search methodology

#### **Search terms**

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Older spouses, caregivers  
Older spouse, caregiving  
Older spouses, caregivers, challenges  
Older spouses, caregivers, gender  
Older spouses, caregivers, health impact  
Older spouses, caregivers, demographics  
Older spouses, caregivers, Canadian demographics  
Caregiver, Canada  
Caregiver, spouse  
Caregiver, spouse, senior  
Caregivers, experiences  
Caregivers, demographics  
Caregivers, challenges  
Caregivers, social support systems  
Caregivers, gender  
Caregivers, health impact  
Caregivers, health promotion  
Caregivers, social networks, support  
Caregiving, self care  
Caregiving, intimacy  
Caregiver, intimacy, spouse  
Caregiving, assessment  
Caregiving, assessment, health  
Caregiver assessment  
Caregiver burden  
Caregiver stress  
Health promotion, caregiver, older adults  
Health, older adults, caregiver  
Social isolation, caregiving

#### **Database**

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Databases were utilized through Mount Saint Vincent University web access:

Academic Search Premier	Psychology (PSY)
Ageline	PSYC articles
Education Research Complete	ProQuest
EBSCO Host	Soc INDEX
ERIC (Educational Resources Information)	
Gender Studies	
Humanities International Complete	
Sociology (SOC)	

*draft*