

Supporting people who care for older family members

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In Canada, there are an estimated four million people caring for older family members with short- or long-term health conditions.¹ A recent Canadian study estimated the cost of such unpaid caregiving at \$25 billion.² Global costs of informal care related just to dementia are estimated to be a staggering \$252 billion of the \$604 billion in societal costs.³

Family caregivers are an integral, yet increasingly overburdened, group providing care within our health care system. Defined by the World Health Organization as those who provide informal unpaid care,³ family caregivers contribute immeasurably to the support of vulnerable older adults. However, this is not without physical, emotional and financial costs to the caregiver.⁴ Time pressures, financial concerns and childcare issues can be overwhelming. Given the essential role of caregivers within the health care system, supporting them has become a global public health priority.

Many older Canadians with complex health conditions are receiving limited hours of publicly funded home care services and therefore rely on family caregivers.⁵ As a result, a large number of family caregivers are stretched beyond their capacity and report high levels of stress.⁵ According to a 2012 Canadian survey, most caregivers are between 45 and 64 years of age and typically spend three or more hours per week providing care to older family members.⁶ The most common types of care include transportation, house cleaning, meal preparation, house maintenance and outdoor work. More than one-quarter of caregivers are “sandwiched” between caring for parents and raising children.⁶ Overall, 28% of caregivers said they would like more assistance, financial or otherwise.⁶ The increasing size of older populations worldwide raises concerns about the continued ability of families to provide the level of care needed to allow older adults to remain in their own homes.

Many older adults prefer to live at home for as long as possible.⁵ However, the burden on and the distress among family caregivers is ever increasing. These effects are particularly evident among those who provide more than 21 hours of care per week and those who support older adults with depression, moderate to severe cognitive decline

or aggressive behaviour.⁷ The challenges associated with supporting individuals with these types of conditions add to the strain on and wear down the resilience of caregivers. People who care for family members with life-limiting conditions have the added stress and emotions associated with losing a loved one. These factors place caregivers at risk of being compromised themselves.

With the multiple challenges faced by caregivers,⁴ the result may be a deterioration of the caregiver’s physical and mental health, social isolation, family conflict and lost income.^{4,8} In the 2012 survey, 46% of caregivers caring for spouses and 30% of those caring for parents reported at least five symptoms of psychological distress, such as depression, feelings of isolation and disturbed sleep.⁶ It has been reported that caregivers who feel more burdened and distressed while providing support have more difficulties adjusting during bereavement.⁴ Caregiver stress may also increase the risk of elder abuse.⁹ Therefore, caregivers require support from the health, social, financial and legal systems to ensure that they can continue to provide care while maintaining their own well-being.

Various types of caregiver support have been evaluated. One systematic review suggested that respite care, individual and group caregiver support, and technology-based interventions may be helpful.¹⁰ Factors that can affect the success of interventions include the degree of caregiver involvement, the extent to which programs are individualized, access to information and coaching, and the type and impact of the behaviour of the care recipient.¹¹ An array of evidence-based programs for caregivers of family members with dementia exists, from counselling and skills training to telephone- and Internet-based service delivery

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KEY POINTS

- Family caregivers are an important source of support to vulnerable older adults.
- Family caregivers are at risk of physical, psychological and financial stresses, alongside the emotional difficulties of caring for an ailing loved one.
- Evidence-based support for family caregivers is not widely available and should be expanded in regional, provincial, national and international efforts to assist family caregivers.

systems. However, these programs are currently not widely available.³ There is a gap between what the evidence shows to be beneficial and what is currently available to most caregivers.

The G8 health ministers recently met at the Dementia Summit in London, United Kingdom, to discuss how to shape an effective international response to dementia, which will need to include appropriate support for people with dementia and their family caregivers.¹² Canada has agreed to play a role in addressing this important global health issue.

Canada has a federal caregiver tax credit; however, only 5% of caregivers providing care to their parents reported receiving this tax credit.⁶ The support available to family caregivers also varies by province. Some other support currently available includes Internet-based resources, such as those provided by the Alzheimer Society of Canada. However, further ways to foster the resilience and strength of caregivers so that they can maintain a supportive presence are critical to the sustainability of the Canadian health care system. The provision of adequate evidence-based support for family caregivers needs to be an important part of regional, provincial, national and international strategies for the care of older adults and those with dementia.

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