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Modern Caregiving in Canada

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Families have always been the main source of support for their members in need of care, whether because of illness, disability or age. Today, the capacity of families to care for their members is being stretched for a variety of reasons. Disability rates across the world are rising and now account for an estimated 15% of the global population. Similar rates can be found in Canada (14.3%), where prevalence increases with age and ranges from 3.7% of children under age 15 to 56.3% of those aged 75 and older.¹

Population aging is another major factor, as it means that more families have adults, seniors and elders requiring care. The senior population (people over age 65) is growing faster than younger cohorts, which includes Canada's "oldest old," who are most likely to be in need of care.² Between 2006 and 2011, the two fastest-growing age groups in Canada were 60- to 64-year-olds (+29.1%) and centenarians (+25.7%).³

The same improvements in preventive health practices and in medical treatment and technology

that have enabled more Canadians to live into late old age have also extended the lifespans of younger adults who have survived catastrophic illness and injury. In the past, such illness and injury would have been fatal, but now survival results in ongoing, often lifelong, care needs instead.⁴

At the same time, smaller families, high rates of women's employment, and geographic mobility among Canadian families may well reduce the supply of potential family caregivers in the future.

Similarly, public sector policies reflect an assumption that families can and should be responsible for providing care to family members.⁵ Community programs have experienced limited growth, and even retrenchment, reducing resources allocated to the health and continuing care service sectors, which is constraining the supply of formal care.⁶ The net result of an escalating demand for care and a simultaneous shrinking supply of both family and formal care is a growing *care deficit*.



Caring for adult, senior and elder family members and friends is becoming a normative mid-life experience.

Nearly half of Canadians have been caregivers

The number of Canadians with family care responsibilities is large and growing. More than one in four (28%) Canadians aged 15 and older, or an estimated 8.1 million, provided care to a chronically ill, disabled or aging family member or friend in 2012. Moreover, nearly half (46%), or 13 million people, said they had been a caregiver to a family member or friend at some time during their lives. These caregivers help their ill, disabled or aging family members with a wide range of daily living needs, including but not limited to housework, yardwork, meal preparation and personal and medical care, enabling them to manage their health and continue to reside in their own homes and communities.⁷

Canadians care out of love and obligation

Canadians willingly care for family members and friends. This is often done in part out of love, a sense of responsibility, duty, commitment or obligation – it is simply something we do for others. Sometimes it can be a “repayment” for having received care or reciprocity for kind or generous acts in the past, or sometimes it can be out of a sense that we might need care ourselves at some time in the future.

But caregiving can also be rewarding. It makes us feel useful as well as confident that our loved one is well cared for, and it can strengthen our relationship with the person we are caring for. It has even been shown in some instances that it helps maintain caregivers’ physical and cognitive well-being.⁸ In 2012, more than nine in ten caregivers (92%) felt that providing care was a rewarding experience and 70% said that their relationship with the care recipient had grown stronger while caring for them over the previous 12 months.⁹

Benefits to Canadians on the receiving end of care, and to society more broadly, are probably more commonly recognized. Care recipients often prefer family care and it is generally assumed that such care is better quality than that delivered by a relative stranger (a paid provider or community volunteer) because the care can be more responsive to the individual, especially if they are unable to express preferences and priorities. Allowing those receiving care to remain in their own home and community can enhance their quality of life. Society also wins when this happens, as it reduces the costs associated with institutional and other formal health care.¹⁰

Caregiving can be detrimental to family finances

Caring for adult, senior and elder family members and friends is becoming a normative mid-life experience. Family caregiving can benefit almost everyone involved, but it also has the potential to *negatively* affect the economic, physical and social well-being of caregivers and the capacity of the family care sector. Furthermore, these potentially harmful effects can accumulate and intensify over the adult life course and spill over to other individuals, organizations or sectors (i.e. employers and community service providers) with a significant impact on performance, productivity, sustainability and prosperity.

Most caregivers are employed (60% of those aged 15 and older in 2012), and fulfilling their paid work and care responsibilities can be challenging.¹¹ In order to effectively manage their multiple roles, some caregivers have to work fewer hours (15% in 2012), miss full or part days of work (43%) or even quit or retire early from their jobs (generally less than 5%).^{12,13} Each of these choices affects caregivers’ earnings and access to employment-related benefits and, ultimately, pension benefits.

Canadian caregivers’ lost wages range from \$100 to \$1,000 per year up to more than \$16,000 per year. This adds up to a whopping \$336.8 million annually during the 2003–2008 period, substantially higher than during the previous six-year period that saw an annual aggregate loss of \$219.3 million.¹⁴ In 2012, 14% of employed caregivers who reduced their hours of work said that they also had lost some or all of their extended health benefits, dental benefits, employer-provided pension, life insurance and prescription drug plans.¹⁵

Caregiving costs may also include paying for residential, home and other care services, medical

and other supplies, and transportation for the care recipient. To free up the time needed to care for another person, caregivers may also need to purchase child care for their children or housekeeping or other services for themselves. Caregivers may also have to pay out-of-pocket for transportation to get themselves to and from the care recipient's residence. In 2007, more than one-third of caregivers aged 45 and older (approximately 1.2 million) made such expenditures.¹⁶ The most common additional expenditures are on household goods, food and meals, transportation and travel. Spending varies, with most spending \$6,000 or less per year, but 3% of caregivers were spending more than \$24,000 annually, totalling \$12.6 million in 2007.

Out-of-pocket expenses can mean that caregivers have less disposable income available for their own immediate and future financial needs, including retirement savings.

Many caregivers have a hard time making ends meet. In 2012, 28% of Canadians caring for a child, 20% of those caring for a spouse and 7% of those caring for a parent reported financial hardship because of their caregiving responsibilities. Some acquired new debt: 10% of those caring for a child borrowed money from friends or family and 12% borrowed from a financial institution.

Public programs that provide financial support in the form of tax benefits, such as the Caregiver Tax Credit, and partial income replacement, such as the Compassionate Care Benefit, can help offset these losses to a degree. However, while the vast majority of caregivers obtain financial help from family and friends, very few benefit from government programs.¹⁷ As a result, many caregivers say that they need more supports in order to continue in their caregiving roles – this was particularly true for surveyed caregivers of a disabled spouse (42%) or child (52%). Ironically, these financial supports have been shown to be associated with a higher likelihood of having care-related expenditures because caregivers often use them to ensure *care recipients'* needs are met rather than their own.¹⁸

Caregiving can take a toll on carers' health

Despite the "healthy caregiver effect" reported for some caregivers, most caregivers report that their caregiving has caused or exacerbated a wide range of physical and psychological health conditions, ranging from body pain, fatigue and exhaustion, to anxiety, stress and depression.^{19, 20}

In 2007, about one in five (more than 537,000) Canadians aged 45 and older reported that their health suffered because of their caregiving responsibilities.²¹ In 2012, nearly four in ten (38%) Canadians aged 15 and older who were caring for their own disabled child or spouse reported that their overall health had been compromised; another



Most caregivers are employed, and fulfilling their paid work and care responsibilities can be challenging.

14% and 8%, respectively, said that they had suffered an injury in the course of their caregiving.²²

Psychological health is affected by caregiving demands. In 2012, more than one-quarter of all regular caregivers reported five or more out of a possible nine symptoms of psychological distress. Psychological distress was especially acute among those caring for parents, spouses and children with long-term health problems (60%, 74% and 82%, respectively, reporting five or more symptoms).²³

In 2007, about one-quarter of Canadian caregivers aged 45 and older whose health had been affected by their caregiving responsibilities sought professional care to address their own care-related health issues. In 2012, about one-third of Canadians aged 15 and older who were caring for their disabled spouse or child reported the same.²⁴

In addition to the direct cost of additional care services for ill or injured caregivers, the cost of providing health care services to the care recipient may also escalate if family caregivers are unable to continue their caregiving activities. Given the estimated \$25–\$26 billion worth of care services provided just by the subset of Canadians aged 45 and older caring for seniors, these costs will be substantial.²⁵



Collaboration and cooperation between families, employers, community organizations, agencies and governments can help ensure that families and family members thrive while mitigating or eliminating the negative consequences of caregiving.



Caregiving can result in social isolation

Erosion of social networks may be responsible, in part, for the negative physical and mental health outcomes and subsequent public health sector costs, as caregiving has been shown to interfere with caregivers' ability to engage normally with their family, friends and communities. Social networks are as important to helping caregivers maintain their own well-being as is the care they provide to the care recipients' welfare.

Yet caregiving has been shown to make it harder for caregivers to spend time participating in social and recreational activities, including those that promote health and wellness. In 2012, about half of caregivers aged 15 and older said their care responsibilities prevented them from spending enough time with spouses, children and friends, taking vacations and engaging in leisure and social events in the community. As a result, nearly one in five said they felt lonely or isolated as a result of their caregiving.²⁶ These social consequences risk undermining caregivers' social networks, which are important sources of companionship and support and provide a feeling of connectedness.

The evidence is clear. The population in Canada is aging. Families and friends are providing the majority of care required by seniors and elders as they age in their own homes and in our communities. Collaboration and cooperation between families, employers, community organizations, agencies and governments can help ensure that families and family members thrive while mitigating or eliminating the negative consequences of caregiving. ▶

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