



A CANADIAN CAREGIVER STRATEGY

A Canada that recognizes,
respects and supports the
integral role of family
caregivers in society



ABOUT THE CANADIAN CAREGIVER COALITION

Established in 2000, the Canadian Caregiver Coalition (CCC) is a virtual coalition of over forty diverse partner organizations that work collectively, and autonomously, to identify and respond to the needs of caregivers in Canada. The CCC's vision is 'A Canada that recognizes, respects and supports the integral role of family caregivers in society'. The CCC is governed by four Signatory Organizations (Canadian Home Care Association, CSSS Cavendish University Institute, Saint Elizabeth and We Care Home Health Services) who ensure the collective interests of the partners are respected, obligations are fulfilled, and the operational structure is effectual.

For more information, visit our website at www.ccc-ccan.ca

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A PICTURE OF FAMILY CAREGIVERS

FAMILY CAREGIVERS PROVIDE care and assistanceⁱ for family or significant people who need support due to debilitating physical, mental or cognitive conditions. A family caregiver's effort, understanding and compassion enable care recipients to live with dignity and to participate more fully in society. For the 8 million family caregivers in Canada, the health conditions requiring care are significant. According to Statistics Canada, 28 percent of caregivers provide care to a loved one with age-related conditions. Cancer is the second most common ailment with 11 percent, followed by cardio-vascular disease at 9 percent, and mental illness at 7 percent¹. The complex and longstanding nature of these conditions are also reflected in the length and intensity of care provided by family caregivers. On average, they provide between 16 – 28 hours of care per month²; and for the vast majority (89 percent) of caregivers the duration of care is one or more years³.

The abrupt nature of the caregiver role impacts individuals of all ages, genders and income strata. Caregivers hail from all walks of life; often undertaking caregiving responsibilities due to sudden health crises, and commonly, the onset of chronic conditions. Twenty-eight percent of Canadians report having cared for a chronically ill, disabled, or aging family member or close friend in the past 12 months⁴.

“It’s not if, it’s when you will be a family caregiver”

NADINE HENNINGSEN, *President, Canadian Caregiver Coalition*

Caregiving does not come without a cost. Many family caregivers (41 percent) use their personal savings to weather their financial hardships, and spend \$100 to \$300 per month on expenses directly related to their caregiver responsibilities⁵. Employed family caregivers face many challenges including increased work interruptions, reduced productivity, missing work days, reducing work hours or foregoing job opportunities. A 2012 Statistics Canada study found that 43 percent of caregivers reduced their work hours because of caregiving responsibilities⁶. The employment consequences of caregiving represent an excessive loss of productivity to employers and to the economy in general - the equivalent of 157,000 full time employees annually⁷.

For young family caregivers (generally aged 7 to 18), assuming the responsibility of caregiving for a parent, grandparent or family member is often accompanied by the negative effects of stress, anxiety and social isolation. Young family caregivers face unique challenges including completing their education, maintaining social circles, and making important decisions about their future. Instead of balancing work and familial obligations, young caregivers must balance the demands of school and social time, often at the risk of failing to acquire the social skills and education required for future success and well-being⁸.

“The effort is worth it to see that your loved one is comfortable, safe and cared for. You will not come out of the experience the same person that you went into it”⁹.

MUFFET, *dedicated family caregiver (Alzheimer’s Association 2013)*

ⁱ Caregiver tasks can include wound dressing and injections, delegated by the health care professional; personal care such as bathing, dressing, feeding or toileting; support activities such as preparing meals, household management, managing medication or attending to finances; and activities such as coordinating the myriad of services that care receivers may need.



WHY A CANADIAN CAREGIVER STRATEGY?

WHILE PROVIDING CARE for loved ones, friends and neighbours is not a new concept, the context of caring is different. Social and economic conditions have changed significantly; and with our aging population, shrinking workforce and unstable global economy, the impact will be further exacerbated over time.

The family unit is growing smaller, more diverse and dispersed. Employment opportunities and expectations are changing, with more women entering the workforce later in life and more individuals delaying retirement. Our population is aging and life expectancy is increasing along with incidents of chronic disease or injury. These socio-economic changes have a significant impact on family caregivers and their ability to work, participate in their community and care for their loved one.

“Health is a chance, caregiving is a choice.”

BRETT H. LEWIS, *Author, Family Caregiving*

Our health and social systems for caring are, and will continue to be, challenged to meet growing demand with limited resources, and manage rising costs within limited budgets. Family caregivers are the invisible backbone of our health care system and provide over 80 percent of the care needed by individuals with ‘long-term conditions’¹⁰. A 2009 study estimated the imputed economic cost to replace family caregivers with the paid workforce (at current market rates and usual employee benefits) totalled \$25 billion¹¹. This equates to 14 percent of the total health care expenditures in Canada¹². Family caregivers must be recognized, valued and protected from the often adverse consequences of having to care too much.

SCOPE OF THE STRATEGY

This Strategy affects over 8 million caregivers and their families across Canada.

According to Statistics Canada, in the past 15 years the number of Canadian caregivers has increased by over 5 million, from 2.85 million in 1997¹³ to over 8 million in 2012¹⁴. Caregivers come from all walks of life – old and young, female (predominantly) and male (increasingly), and from all income levels. Eighty-four percent of caregivers provide care to close family members, including their parents or parents-in-law (48 percent), grandparents (13 percent), siblings (10 percent), spouses (8 percent) and children (5 percent)¹⁵. Beyond the direct family unit, 16 percent of carers are friends, neighbours and colleagues¹⁶.



CAREGIVERS LIKE... Tom and Martha, a 75-year old couple living with their 45-year old son, Paul, who has schizophrenia. Paul is unable to care for himself without supervision. Tom and Martha are getting older and are finding it more difficult to address Paul's needs. Because Paul does not have a specific physical disability in addition to schizophrenia, he is ineligible for help through a home care program. Tom and Martha spend countless hours every month caring for their son and worry constantly about his future.



It affects the 5.0 million Canadian seniors.

Projections by Statistics Canada indicate that, in 2011, an estimated 5 million Canadians were 65 years of age or older (14 percent of the population), a number that is expected to double in the next 25 years to 10.4 million (23 percent of the population). Presently, age related conditions are the most common ailments that jeopardize an individual's ability to live independently in the community. As the prevalence of age-related chronic conditions grows, the demand on family caregivers will correspondingly increase.



SENIORS LIKE... Claude who is struggling to care for his wife Marie (83) who has Alzheimer's disease. Her condition and health have been deteriorating and she has progressed to the palliative stage. Claude has promised Marie to let her die at home. Claude is 87 and has several chronic conditions, including heart disease and arthritis. Claude is exhausted from the years of caregiving and his own failing health.

It affects the 2.3 million¹⁷ employed family caregivers.

Employed caregivers must balance the competing demands of work and caregiving. This often results in negative employment consequences such as missing work days, reducing work hours or foregoing job opportunities. These consequences have economic costs for caregivers, their families and their employers. In 2011, over 520,000 employed caregivers missed one or more days of work per month to provide care; collectively this equalled 1.48 million days / month. Additionally, over 313,000 employed caregivers reduced their work hours to accommodate care responsibilities. This reduction in paid work hours also impacts employee benefits, with 14 percent of employed caregivers reporting losses in health benefits, dental benefits, employer provided pension, life insurance and prescription drug plans¹⁸.



EMPLOYEES LIKE... Sarah and George, a young couple caring for their three-year old daughter Clara, who has cerebral palsy. Sarah had to quit her job when it was determined that Clara's needs (tube feedings, suctioning, bathing, toileting, dressing, feeding, exercise, mobility, etc.) greatly exceeded the services provided by the home care program in her province. George travels a great deal with his job and, like many other couples who have children with significant care needs, their relationship is strained and vulnerable. Their son is beginning to act out and to complain that his mother only has time for Clara. Sarah is exhausted, their financial and family situation is strained, and they are both feeling overwhelmed with no end in sight.

It affects every Canadian.

Canadians across the country who are providing care for family members and loved ones require support from all levels of government. The coordination of federal, provincial and municipal initiatives is critical to an effective caregiver strategy. However, government alone cannot achieve a vision of "A Canada that recognizes, respects and supports the integral role of family caregivers in society." All elements of society, including the public and private sectors, and individual Canadians, must work together to achieve the vision.



GUIDING PRINCIPLES OF THE STRATEGY

THESE GUIDING PRINCIPLES serve as the foundation to the Canadian Caregiver Strategy. Application of these principles will ensure the perspectives and needs of family caregivers, their families and those close to them are considered and addressed in any activity and decision-making that affects them.

RESPECT:

Family caregivers are acknowledged, respected and valued for their caregiving work.

CHOICE:

Family caregivers have a choice to become partners in care and have the right to choose the degree of their involvement at every point on the continuum of care.

SELF-DETERMINATION:

Family caregivers have the right to express their needs and receive support.

ESSENTIAL ELEMENTS OF THE STRATEGY

FIVE KEY ELEMENTS address the priorities identified by family caregivers and organizations that support them. They serve as a reference for the development of legislation, policy and programs that support this vital role.

- 1 SAFEGUARD THE HEALTH AND WELL-BEING OF FAMILY CAREGIVERS.
- 2 MINIMIZE THE FINANCIAL BURDEN PLACED ON FAMILY CAREGIVERS.
- 3 ENABLE ACCESS TO USER FRIENDLY INFORMATION AND EDUCATION.
- 4 CREATE FLEXIBLE WORKPLACE / EDUCATIONAL ENVIRONMENTS THAT RESPECT CAREGIVING OBLIGATIONS.
- 5 INVEST IN RESEARCH ON FAMILY CAREGIVING AS A FOUNDATION FOR EVIDENCE-INFORMED DECISION MAKING.

OUTCOMES OF THE STRATEGY

Progress on the Strategy

An essential part of keeping the Strategy vibrant and effective is a joint commitment between government and stakeholders. The Canadian dialogue is increasingly turning to the well-being of family caregivers. This momentum is reflected in the introduction of federal and provincial legislation and programs recognizing the contribution of family caregivers across Canada. Gains and successes that have been achieved over the past five years includeⁱⁱ (but are not limited to):

“Our Government’s plan also recognizes the tremendous time and resources required of family caregivers.”

GOVERNOR GENERAL DAVID JOHNSTON, *Speech from the Throne, 2011*

ii For a more detailed overview of the progress on the Caregiver Strategy across Canada visit the CCC website at www.ccc-ccan.ca.



- The introduction of the **Federal Family Caregiver Tax Credit** in 2011 grants tax relief to care providers of infirm dependent relatives. Caregivers are eligible for an additional non-refundable credit of \$2,040 in recognition of their significant contribution¹⁹.
- The **Nova Scotia Caregiver Benefit Program** mitigates the cost of caring through providing \$400 monthly to caregivers of low income care recipients. This financial support is also key in allowing for caregiver self-care²⁰.
- In June of 2011, the province of Manitoba passed Bill 42: the **Caregiver Recognition Act**. This progressive legislation calls for improved awareness, recognition and support for carers, and is also the first of its kind²¹.
- The **Alzheimer Society's First Link** is a referral program designed to connect dementia patients and their caregivers with key services and supports, at both the time of diagnosis and throughout the duration of the disease. The program is currently offered in British Columbia, Alberta, Saskatchewan, Manitoba, Ontario, and Newfoundland and Labrador²².
- **CareAware** is an innovative provincial program that aims to raise awareness in support of Manitoba's family caregivers. CareAware workplaces utilize a caregiver support framework that includes implementing a positive workplace culture, flexible work programs and open access to information and supports, thus enabling balance between work and caregiving responsibilities²³.
- **Canadian research initiatives** are increasingly exploring the integral role family caregivers play in Canada's aging society. Research initiatives include examination of caregiving in the context of family dynamics, an aging population and work/life balance.

Building on the Momentum

As the progress continues, it is crucial that tangible, measurable outcomes that impact family caregivers are both identified and embraced.

- **CAREGIVERS ARE RECOGNIZED AND THEIR NEEDS ARE IDENTIFIED:** Family caregivers are assessed for their specific needs and provided with emotional, psychological and physical support in order to sustain their continued contribution to the provision of care.
- **ACCESSIBLE AND FLEXIBLE RESPITE:** Health care and social programs provide adequate support and respite services tailored to the diverse needs of caregivers.
- **UNDUE FINANCIAL BURDEN IS ALLEVIATED:** Caregivers can access a range of financial relief options that alleviate out-of-pocket expenses and address reduced income due to loss of capacity to maintain full or stable employment.
- **CAREGIVERS HAVE APPROPRIATE INFORMATION AND SUPPORT SYSTEMS:** Family caregivers have access to information and support programs to help them fulfill their caregiving role in a sustainable and safe manner.
- **EMPLOYERS PROVIDE FLEXIBLE WORKPLACE OPTIONS THAT RESPECT CAREGIVERS OBLIGATIONS:** Employers provide flexible working arrangements, personal leave, benefits and wellness strategies, such as counselling, in support of the working caregiver.
- **EDUCATIONAL PROGRAMS RECOGNIZE AND RESPECT YOUNG FAMILY CAREGIVER NEEDS:** Supports and resources in schools and universities and colleges support the unique needs of young carers.
- **EVIDENCE-BASED DECISION MAKING IS SUPPORTED:** Research and knowledge dissemination on all aspects of caregiving, including health care outcomes, impacts of policies and services, best practices, economic dimensions and psychosocial aspects of carers of all ages are supported.



ACHIEVING A VISION FOR CAREGIVING IN CANADA

'A Canada that recognizes, respects and supports the integral role of family caregivers in society'

FAMILY CAREGIVERS take pride in their role, and we, as Canadians, should be proud of our caring society. This Framework, developed by the Canadian Caregiver Coalition, is a foundational piece to facilitate collaborative action planning, and ensure family caregivers have a voice in this dialogue. Across the country, caregivers are calling for recognition and assistance. It is time for bold actions, clear policies and all-inclusive legislation to support the 8 million caregivers who have shown a dedication and commitment to providing care and whose caring offsets substantial public costs, often at the expense of personal health and financial wellbeing.

Formal recognition of and respect for the valuable role of family caregivers in ensuring the sustainability of our health care system, and the continuing prosperity of our country, is a priority for all Canadians. We call upon federal, provincial and municipal governments, the public and private sector organizations and individual Canadians to achieve our vision of "A country that recognizes, respects and supports the integral role of family caregivers in society".

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