



# A CANADIAN CARER STRATEGY

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



## ABOUT THE CARERS CANADA

Carers Canada (formally known as Canadian Caregiver Coalition), established in 2000, is an alliance of diverse partner organizations that work collectively, and autonomously, to identify and respond to the needs of carers in Canada. Carers Canada's vision is "a Canada that recognizes, respects, and values the integral role of carers in society". Our mission is to enhance the quality of life for carers through synergistic partnerships and global advocacy that strengthens and honors the voice of carers.

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## A PICTURE OF CARERS

**A CARER** (also referred to as caregiver or family caregiver) is a person who takes on an unpaid caring role for someone who needs help because of a physical or cognitive condition, an injury or a chronic life-limiting illness. A carer'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 percent. The complex and longstanding nature of these conditions are also reflected in the length and intensity of care provided by carers. On average, they provide between 16 – 28 hours of care per month; and for the vast majority (89 percent) of caregivers the duration of care is one or more years<sup>1</sup>.

*“It’s not if, it’s when you will be a carer”*

NADINE HENNINGSEN, *President, Carers Canada*

**Caregiving does not come without a cost.** Many carers (41 percent) use their personal savings to cover unexpected costs, and spend \$100 to \$300 per month on expenses directly related to their caregiving responsibilities<sup>2</sup>.

For young carers (generally aged 7 to 18), assuming the responsibility of caregiving for a parent, grandparent or family member often results in increased stress, anxiety and social isolation. Young carers 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-being<sup>3</sup>.

*“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.”*

MUFFET, *dedicated carer (Alzheimer’s Association 2013)*

## WHY A CANADIAN CARER STRATEGY?

**WHILE PROVIDING CARE** for loved ones, friends and neighbours is not a new concept, the context of caring has changed. 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. These socio-economic changes have a significant impact on carers and their ability to work, participate in their community and care for their loved one.

Our health and social systems will continue to be challenged to meet growing demand with limited resources, and manage rising costs within limited budgets. Carers are the invisible backbone of our health care system and provide over 80 percent of the care needed by individuals with ‘long-term conditions’<sup>4</sup>. 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 billion<sup>5</sup>. This equates to 14 percent of the total health care expenditures in Canada<sup>6</sup>. 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 carers and their families.

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 1997<sup>7</sup> to over 8 million in 2012<sup>8</sup>. Carers 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). Beyond the direct family unit, 16 percent of carers are friends, neighbours and colleagues<sup>9</sup>.



**CARERS LIKE...** Evelyn, a Personal Support Worker, who stretches her time to care for her husband, six kids and sick father. “I have to visit my father in between my client visits and do whatever I need to do for him. It is like you are working all the time—24-hour care. Your mind is always on his needs, my family needs and work needs,” she says. Despite its challenges, Evelyn finds the strength to keep her going. “When you love someone, you appreciate them and you want to help them,” she says. “I believe there is a time for everything. This is my time to help my father”

### 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 carers 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 million<sup>10</sup> employed carers.

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 plans<sup>11</sup>.



**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 all Canadians.



# GUIDING PRINCIPLES OF THE STRATEGY

- RESPECT:** Carers are acknowledged, respected and valued for their caregiving work.
- CHOICE:** Carers have the right to choose the degree of their involvement in care.
- DISTINCTIVE:** Carers have the right to express their needs and receive support.

## UNIVERSAL CARER PRIORITIES

**FIVE PRIORITY AREAS** address the needs identified by carers and organizations that support them and serve as a reference for the development of legislation, policy and programs.

### 1 Safeguard the health and well-being of carers.

- **Carers are recognized and their needs are identified:** Carers are assessed for their specific needs and provided with emotional, psychological and physical support.
- **Accessible and flexible respite:** Support and respite services tailored to the diverse needs of carers.

### 2 Minimize excessive financial burden placed on family carers.

- **Financial options:** Carers can access a range of options that alleviate out-of-pocket expenses and address reduced income due to employment loss.
- **Compassionate Care Benefit:** Carers can easily access flexible and appropriate compensation to meet their needs.
- **Caregiver tax credit and other tax benefits:** Carers easily access financial measures.
- **Access to social workers and financial experts:** Carers are assisted to navigate and access social and financial supports.

### 3 Enable a carers to access user friendly information and education.

- **Access to support groups:** Carers can meet to share knowledge and reduce the sense of isolation.
- **Access to mental health professionals:** Carers who experience emotional distress are supported and heard.
- **Carers are partners in care:** Health care providers share understandable and detailed information to carers about their loved one's health condition and trajectory of illness.
- **Technology enabled carers:** Carers use technology to support safe, effective care, gain knowledge and communication with others.

### 4 Create flexible workplace/educational environments that respect caregiving obligations.

- **Flexible workplace options:** Employers provide flexible arrangements, personal leave, benefits and wellness strategies.
- **Modified educational programs:** Supports and resources in schools and universities and colleges support the unique needs of young carers.

### 5 Invest in research on family caregiving as a foundation for evidence-informed decision making.

- **Research and knowledge dissemination** is funded and applied to carer policies and programs.



# ACHIEVING A VISION FOR CAREGIVING IN CANADA

*'A Canada that recognizes, respects and supports the integral role of carers in society'*

**CARERS** take pride in their role, and we, as Canadians, should be proud of our caring society. This strategy, developed by Carers Canada, is a foundational piece to facilitate collaborative action planning, and ensure carers have a voice in this dialogue. Across the country, carers are calling for recognition and assistance. It is time for bold actions, clear policies and all-inclusive legislation to support the 8 million carers 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 carers, 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 carers in society”.

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- 3 Grant Charles, Tim Stainton & Sheila Marshall, School Of Social Work, University Of British Columbia, 2012 Young Carers in Canada The Hidden Costs and Benefits of Young Caregiving, The Vanier Institute of the Family.
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- 8 Statistics Canada. (2013). Portrait of caregivers, 2012. Catalogue no. 89-652 X- No.001. Ottawa, ON: Statistics Canada Social and Aboriginal Statistics Division, retrieved from <http://www.statcan.gc.ca/pub/89-652-x/89-652-x2013001-eng.htm>
- 9 Ibid
- 10 Statistics Canada's 2007 General Social Survey (GSS).
- 11 Statistics Canada. (2013). Portrait of caregivers, 2012. Catalogue no. 89-652 X- No.001. Ottawa, ON: Statistics Canada Social and Aboriginal Statistics Division, retrieved from <http://www.statcan.gc.ca/pub/89-652-x/89-652-x2013001-eng.htm>