

# A Framework for a Canadian Caregiver Strategy

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



Canadian Caregiver Coalition  
La coalition canadienne des aidantes et aidants naturels  
[www.ccc-ccan.ca](http://www.ccc-ccan.ca)

## **The Canadian Caregiver Coalition**

The Canadian Caregiver Coalition (CCC) is a diverse group of federal and provincial organizations that join with caregivers, service providers, policy makers and other stakeholders to identify and respond to the needs of caregivers in Canada.

The vision of the Canadian Caregiver Coalition is a Canada that recognizes and respects the integral role of family caregivers in society, and supports this role with the understanding that it is not a substitute for public responsibility in health and social care.

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# A Framework for a Canadian Caregiver Strategy

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

## Who are Family Caregivers?

“Family caregivers” provide care and assistance<sup>1</sup> for spouses, children, parents and other extended family members and friends who are in need of support because of age, disabling medical conditions, chronic injury, long term illness or disability. A family caregiver’s effort, understanding and compassion enable care recipients to live with dignity and to participate more fully in society. The intensity and length of caregiving can be significant with over 700,000 caregivers providing more than 10 hours of care per week and 60% of caregivers providing care for more than three years.<sup>2</sup>

Caregivers come from all walks of life – old and young; female (predominantly) and male (increasingly); and can be found across all income strata. Caregiving responsibilities can occur suddenly; are typically chronic; and do not always have a happy outcome.

*Caring responsibilities impact a caregiver’s social and working life.*

Caregivers provide more than 80% of care needed by individuals with ‘long-term conditions’ and it is estimated contribute more than \$5 billion of unpaid labour annually to the health care system.<sup>3</sup> 26% of Canadians report having cared for a family member or close friend with a serious health problem in the last 12 months, with 22% of these people missing one or more months of work and 41% using personal savings.<sup>4</sup>

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<sup>1</sup>Caregiver tasks can include wound dressings and injections, delegated by the health care professional; personal care such as bathing, dressing, eating 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 require.

<sup>2</sup>Health Canada. (2002). National Profile of Family Caregivers in Canada - Final Report. [www.hc-sc.gc.ca](http://www.hc-sc.gc.ca)

<sup>3</sup>Fast, J., Niehaus, L., Eales, J., & Keating, N. (2002a). A profile of Canadian chronic care providers, submitted to HRDC

<sup>4</sup>Pollara. (2006). Health Care in Canada Survey. [www.hcic-sssc.ca](http://www.hcic-sssc.ca)

## Why a Canadian Caregiver Strategy?

The concept of family caregiving is not new. However, the context for caring today is different – the social and economic circumstances have changed significantly over time.

Families are smaller and more dispersed; there are more women in the formal workforce; marriage and childbearing occur later in life; retirement is delayed; the population is aging; and there is an increased life expectancy which will likely involve a disability. Additionally, health systems across the country are undergoing significant reform in order to respond to the changing health care needs of Canadians.

*It's not if, it's when you will become a caregiver.*

Today's reality is that the formal and informal system for caring are, and will continue to be, challenged to meet the desire of Canadians to receive care at home. Family caregivers must be supported, recognized and protected from the sometimes adverse consequences of having to care too much.

### Scope of the Strategy

This Strategy affects all Canadians. The Canadian Caregiver Coalition estimates that there are over 4 million family caregivers in Canada. According to a 2008 Statistics Canada report, 2.7 million caregivers are aged 45 and over, an increase of 670,000 between 2002 and 2007. This number is expected to grow as our population ages and requires support to remain independent at home.

All levels of government must engage in initiatives to provide support and assistance to Canadians across the country that are providing care for their family members and loved ones. However, government alone cannot address what is necessary to make the vision happen. All parts of society including the public and private sectors must work together to help achieve the vision for family caregiving in Canada.

# VISION FOR FAMILY CAREGIVING IN CANADA

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A CANADA THAT RECOGNIZES AND RESPECTS THE INTEGRAL ROLE OF FAMILY CAREGIVERS IN SOCIETY, AND SUPPORTS THIS ROLE WITH THE UNDERSTANDING THAT IT IS NOT A SUBSTITUTE FOR PUBLIC RESPONSIBILITY IN HEALTH AND SOCIAL CARE.

## Guiding Principles

The following guiding principles serve as the foundation to the 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 activities 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

The value Canadians place on family caregiving must be acknowledged in legislation, policy, and practice. To this end, these key elements address the priorities that have been identified by family caregivers and organizations that support them and should serve as a reference for the development of a Caregiver Strategy. Meeting these priority areas is vital to bringing Canada closer to achieving the vision for family caregivers.

- Safeguarding the health and wellbeing of family caregivers and increasing the flexibility and availability of respite care
- Minimizing excessive financial burden placed on family caregivers
- Enabling access to user friendly information and education
- Creating flexible workplace environments that respect caregiving obligations
- Investing in research on family caregiving as a foundation for evidence-informed decision making

## Outcomes of the Strategy

A key part of keeping the Strategy vibrant and effective is a partnership of commitment to the Strategy between government and stakeholders. No one individual entity is responsible for ensuring everything happens. It is crucial that this Strategy has tangible measurable outcomes and is sufficiently resourced.

- Health care and social programs provide adequate support tailored to the diverse needs of caregivers.
- 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.
- Caregivers who must leave paid employment or curtail self-employed work in order to provide care can access job protection provisions and income support.
- Financial measures offset caregiving expenses and employment related benefits for family caregivers.
- Family caregivers have access to information and training programs which they may require to address the many issues involved in caregiving and to fulfill their role in a sustainable and safe manner.
- Knowledge about all aspects of caregiving, including health care outcomes, impacts of policies and services, best practices, economic dimensions and psychosocial aspects of family caregiving is generated and shared.
- All jurisdictions work together and independently to implement the Strategy and develop a common standard of care and services for family caregiving across Canada.
- Monitoring and evaluation is used to continuously enhance the nature and quality of the implementation of the Strategy.

## Conclusion

Family caregivers are proud of what they do, and Canada should be proud of its family caregivers. This Framework, developed by the Canadian Caregiver Coalition<sup>5</sup> is the first step to giving family caregivers a real voice and to encouraging collaborative joint action planning between and among the many stakeholders.

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