

CANADIAN CAREGIVER COALITION
COALITION CANADIENS DES PROCHES AIDANTS

2014 PRE-BUDGET CONSULTATION
For the 2015 Federal Budget

Submission to the
House of Commons Standing Committee on Finance

Date: August 6th, 2014

Championing the interests of family caregivers across Canada.



À la défense des intérêts des proches aidants partout au Canada.

EXECUTIVE SUMMARY

The Canadian Caregiver Coalition (CCC) welcomes the opportunity to provide input to the House of Commons Standing Committee on Finance as it prepares for the 2015 Federal Budget. Our submission makes specific recommendations with the intent of protecting the rights of family caregivers to live with dignity and to participate more fully in society. Enactment of these recommendations will not only better support the full spectrum of caregivers, but also provide an avenue to *Seizing Canada's Moment: Prosperity and Opportunity in an Uncertain World*, principle of the 2013 Speech from the Throne. These recommendations will advance Canada's unique set of indelible qualities: inclusive, honourable, selfless, caring and smart.

Focusing on family caregivers through a national agenda has never been more urgent. To this end, the CCC proposes two recommendations for the Federal Government:

- 1. Allocate a \$ 3 million project fund to support the CCC in engaging front-line stakeholders and decision makers to accelerate the development of concrete strategies that will move key priorities of the Canadian Caregiver Strategy into action.**
- 2. Expand the Employment Insurance Compassionate Care Benefit (CCB) to alleviate financial stress and support the vital role of family caregivers.**

BACKGROUND

Family caregivers are family members and other significant people (as identified by the care recipient) who provide care and assistance to individuals living with a debilitating physical, mental or cognitive conditionⁱ.

Although providing care for a loved one, friend, or neighbour is not a new concept, the context of caring is different. Caring for family, friends and loved ones, once one of the most personal and private matters in family life, is becoming one of the most important social policy issues in Canada and the world.

The rapid aging of Canada's population and the increase in life expectancy will be accompanied by a growth in the prevalence of elderly people who are frail, disabled, experiencing a decline in cognitive function, or have multiple chronic conditionsⁱⁱ. These are all risk factors that will cause difficulty for individuals to perform essential daily activities and thereby, creating a greater dependency on others.

The changing family structure also impacts the availability and role of family caregivers. The combined effects of later marriage, increased participation of women in the labour force and delayed child bearing have increased the number of caregivers in the sandwich generation balancing career and family responsibilitiesⁱⁱⁱ. In comparison to thirty years ago, today's Canadian families are much smaller with fewer children available to fill the gaps in our health care system and provide care for the increasing number of elderly family members^{iv}.

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Family caregivers are the invisible backbone of our health care system

Over past 15 years the number of caregivers in Canada has increased by over 5 million, from 2.85 million in 1997 to over 8 million in 2012^v. Currently, three quarters of the care recipients are at least 75 years old, with one third being 85 or older^{vi}. It has also been noted that 1 in 4 of caregivers are seniors themselves (i.e. spousal caregiving) who may not be able to provide extensive care or require assistance themselves^{vii}. The increase in the number of caregivers can be attributed in part to a fundamental shift to the provision of health care in the home. The number of Canadians receiving home care has increased by 55 percent to over 1.4 million from 2008-2011^{viii}. All home care programs are designed to complement, not replace, the efforts of individuals to care for themselves, with the assistance of family, friends and community. As the demand for home care increases the demands on family caregivers will grow.

Caregivers come from all walks of life – old and young, female (predominantly) and male (increasingly), and from all income levels. On average, they provide between 16-28 hours of care per month^{ix}; and for the vast majority (89 percent) the duration of care is one or more years^x. Family caregivers provide over 80 percent of the care needed by individuals with ‘long-term conditions’^{xi}. 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^{xii}.

As iterated by the Governor General David Johnson’s 2013 Speech from the Throne, “Families are the cornerstone of our great country. Helping families care for their loved ones and save for the future helps reinforce our bonds as a society and ensures that the next generation is able to thrive.... As our families succeed, Canada succeeds. Our Government understands the daily pressures ordinary Canadian families face. And it is working to strengthen families, not replace them.”^{xiii}

RECOMMENDATIONS

The CCC commends the Federal Government for the initiatives and actions they have taken to recognize and support the vital role of family caregivers through tax measures and targeted programs. A great deal has been accomplished; however more needs to be done.

RECOMMENDATION # 1: Allocate a \$ 3 million project fund to support the CCC in engaging front-line stakeholders and decision makers to accelerate the development of concrete strategies that will move key priorities of the Canadian Caregiver Strategy into action.

The CCC applauds the Federal Government for taking a leadership role in advancing the development of community-integrated palliative care models across Canada through the targeted funding in the Economic Actions Plans in 2011 and 2013. These substantial contributions demonstrate the government’s recognition of their impactful role in making significant change happen for vulnerable Canadians across Canada.

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Building on this commitment, the CCC recommends that the Federal Government address the unique needs of family caregivers who provide care and assistance to the growing number of Canadians living with life-threatening conditions. Through the allocation of a \$3 million project fund, the CCC and its partners will engage front-line stakeholders across the country to identify concrete actions to advance the five priority areas identified in the Canadian Caregiver Strategy. Identified through extensive consultations with family caregivers across Canada, the Canadian Caregiver Strategy outlines five priority areas for action:

1. Safeguard the health and well-being of family caregivers
2. Minimize excessive financial burden
3. Enable access to user friendly information
4. Create flexible workplace and educational environments
5. Invest in research on family caregiving

Rationale: Most Canadians with life-threatening illnesses would prefer to die at home surrounded by family and friends, yet approximately 70 percent of deaths in Canada still occur in hospital or long-term care facilities. This reality is reflected in a recent Harris Decima survey of Canadians “If Canadians have a preferred setting for end-of-life, it’s more likely that they prefer it to be in the home...At the same time, there is a sense that they will not be able to receive the bulk of the care leading up to their end-of-life in the home; more expect it will be in a hospital.”^{xiv}

RECOMMENDATION # 2: Expansion of the Employment Insurance Compassionate Care Benefit (CCB) to alleviate financial stress and support the vital role of family caregivers.

The federal government’s implementation of the CCB has been seen as a legislative step in the right direction to better supporting family caregivers. However, the current CCB’s narrow eligibility criteria and lack of flexibility renders the benefit unusable by the majority of caregivers. This has resulted in an “inverse care law” – in that , persons most in need may be least likely to apply for reimbursement while those least in need may have more capacity to claim the benefit^{xv}.

The CCC recommends improving the CCB to ensure that the program better meets the needs of all family caregivers by:

- **Extending eligibility to caregivers who are providing support to those who require care due to a chronic long-term condition in addition to life- limiting medical conditions**

Rationale: In 2011/12, CCB claimants used an average of 4.7 weeks (78.2%) of the maximum entitlement of 6 weeks^{xvi}. According to a recent study, the main reason for this is that the care recipient died while the claimant was receiving compassionate care benefits^{xvii}. This situation reinforces the limitations of the CCB eligibility criteria and challenges us to consider how broader criteria could support family caregivers’ involvement throughout the care recipient’s life not just at death.

- **Eliminate the required two-week unpaid waiting period & increase the benefit period from six to twenty six weeks within a fifty two week period**

Rationale: By providing more substantive financial protection, family caregivers from all income strata can provide the necessary care without concerns of how to make ends meet if they are required to take time off work.

- **Broadening eligibility criteria to allow for partial leave over a longer period**

Rationale: Due to the unpredictable needs of individuals living with long-term chronic conditions or life-threatening illness family caregivers require flexible work arrangement. This is especially important for those who cannot afford extended period of an unpaid leave. Flexibility enables caregivers to provide care at the right time which can prevent unnecessary complications in the care recipient's health and relieve caregiver's stress.

How our recommendations will fulfill the 2014 Pre-Budget Consultation Key Themes:

Balancing the federal budget (fiscal sustainability and economic growth):

Providing appropriate supports for family caregivers will enable them to continue to provide care and contribute productively to the labour market. Caregivers are a vital resource for our health care system and supporting their health and well-being results in cost saving overall.

Supporting families and helping vulnerable Canadians:

Enactment of our recommendations will alleviate the negative burden on family caregivers so they are able to balance normal life (work, leisure, family life) with caring, without damaging their health and future well-being. Caregivers need to have equal opportunities to contribute to our society and have healthy, productive lives.

Increasing the competitiveness of Canadian businesses & maximizing the number and types of jobs for Canadians:

Working caregivers must balance multiple responsibilities and often experience negative employment consequences: absenteeism, reducing work hours or foregoing job opportunities. Providing flexible workplaces that respect caregiver needs will reduce over 1.48 million lost days of work/month^{xviii}.

About the Canadian Caregiver Coalition

Established in 2000, the Canadian Caregiver Coalition (CCC) is a virtual alliance of diverse partner organizations that work collectively, and autonomously, to identify and respond to the needs of caregivers in Canada. Our mission is to enhance the quality of life for family caregivers through advocacy and synergistic partnerships. Together we strive to achieve our vision of “a Canada that recognizes, respects, and values the integral role of family caregivers in society”. For more information, visit www.ccc-ccan.ca.

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ⁱ Canadian Caregiver Coalition. (2013). *A Canadian Caregiver Strategy* [PDF]. Retrieved from: <http://www.ccc-ccan.ca/media.php?mid=405>

ⁱⁱ Duxbury, L. & Higgins, C. (2013). *Balancing Work, Childcare, and Eldercare: A View from the Trenches*. Ottawa, ON: SprottSchool of Business & Carleton University, in partnership with Desjardins Insurance.

ⁱⁱⁱ Ibid

^{iv} Ibid

^v Statistics Canada. (2013). *Portrait of Caregivers, 2012*. Catalogue no. 89-652 X- No.001. Ottawa, ON: Statistics Canada Social and Aboriginal Statistics Division

^{vi} Statistics Canada. (2012). *Informal Caregiving for Seniors*. Component of Statistics Canada Catalogue no. 82-003-X. Ottawa, ON: Statistics Canada

^{vii} Statistics Canada. (2008). *Eldercare: What We Know Today*. Component of Statistics Canada Catalogue no. 11-008x. Ottawa, ON: Statistics Canada

^{viii} Canadian Home Care Association. (2013). *Portraits of Home Care in Canada* [PDF]. Retrieved from: <http://www.cdnhomecare.ca/content.php?doc=274>

^{ix} Fast, J. (2005). *Caregiving: A Fact of Life*. *Transition*, 35(2), 4-9. Ottawa, ON: The Vanier Institute of the Family.

^x Statistics Canada. (2013). *Portrait of Caregivers, 2012*. Catalogue no. 89-652 X- No.001. Ottawa, ON: Statistics Canada Social and Aboriginal Statistics Division

^{xi} Fast, J., Niehaus, L., Eales, J., & Keating, N. (2002). *A profile of Canadian chronic care providers*.

^{xii} Hollander, J. M., Liu, G., & Chappell, N. (2009). *Who cares and how much*. *Healthcare Quarterly*, 12(2), 42-49

^{xiii} Governor General of Canada . (2013). *Seizing Canada’s Moment: Prosperity and Opportunity in an Uncertain World*. Speech from the Throne to Open the Second Session of the Forty-First Parliament of Canada. Retrieved from: http://speech.gc.ca/sites/sft/files/sft-en_2013_c.pdf

^{xiv} Canadian Hospice Palliative Care Association. (2013). *What Canadians Say: The Way Forward Survey Report*. Retrieved from: <http://www.hpcintegration.ca/media/51032/The%20Way%20Forward%20-%20What%20Canadians%20Say%20-%20Survey%20Report%20Final%20Dec%202013.pdf>

^{xv} Keefe, J. & Fancey, P. (1999). *Compensating Family Caregivers: An Analysis of Tax Initiatives and Pension Schemes*. *Health Law Journal*, 7, pp.193-204

^{xvi} CEIC. (2012). *2012 EI Monitoring and Assessment Report*. Retrieved from: <http://www.esdc.gc.ca/eng/jobs/ei/reports/mar2012/index.shtml>

^{xvii} Ibid

^{xviii} Statistics Canada. (2013). *Portrait of Caregivers, 2012*. Catalogue no. 89-652 X- No.001. Ottawa, ON: Statistics Canada Social and Aboriginal Statistics Division

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