



# **FAMILY CAREGIVING ADVOCACY AND ACTION**

What if Canada was the best in the world in meeting  
the needs of family caregivers?

Canadian Home Care Association

[www.cdnhomecare.ca](http://www.cdnhomecare.ca)

Canadian Caregiver Coalition

[www.ccc-ccan.ca](http://www.ccc-ccan.ca)

British Columbia Psychogeriatric Association

[www.bcpga.bc.ca](http://www.bcpga.bc.ca)

**The Canadian Home Care Association (CHCA)** is a not-for-profit membership association dedicated to ensuring the availability of accessible, responsive home care and community supports to enable people to stay in their homes with safety, dignity and quality of life. Members of the Association include organizations and individuals from publicly funded home care programs, not-for-profit and proprietary service agencies, consumers, researchers, educators and others with an interest in home care. Through the support of the Association members who share a commitment to excellence, knowledge transfer and continuous improvement, CHCA serves as the national voice of home care and the access point for information and knowledge for home care across Canada.

**The Canadian Caregiver Coalition** is a diverse group of national and provincial organizations from across Canada that works collaboratively to represent and promote the needs and interests of family caregivers with all levels of government, and the community. 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.

**The British Columbia Psychogeriatric Association (BCPGA)** is a professional multi-disciplinary non-profit organization founded in 1997 made up of service providers, educators, program managers and researchers. Members come from a wide range of health and social service settings and from universities and government, in rural and urban communities. This gives BCPGA broad content and systems knowledge that can be brought to bear on our national projects.

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## Executive Summary

On June 8 and 9, 2011, stakeholders representing a broad range of organizations including national associations, charities, coalitions, home care providers, employers, and government and caregiver coalitions convened to explore and identify innovative advocacy practices that will contribute to the successful advancement of the caregiver agenda.

Throughout the 1 ½ day workshop, the participants presented with a challenging question: “What if Canada was the best in the world in meeting the needs of family caregivers? How can we make this statement a reality?”

Informative policy advice and strategies to engage governments were shared by Elizabeth Mulholland, an independent public policy consultant, specializing in social development, sport for development, and innovation policy. Participants applied the lessons learned to develop a concrete action plan to advance three key elements of the Canadian Caregiver Coalition National Caregiver Strategy:

- Safeguarding the health and wellbeing of family caregivers and increasing the flexibility and availability of respite care
- Enabling access to user friendly information and education
- Creating flexible workplace environments that respect caregiving obligations.

**Dr. Penny McCourt and Dr Dawn Hemingway** presented an innovative Caregiver Policy Lens that was developed at the British Columbia Psychogeriatric Association. The objective of the lens is to provide an analytical framework to assess planned and current programs and policies from the perspective of caregivers, and to identify any unintended negative effects on them. Participants immediately recognized the potential of the tool to ensure multi-sectoral consideration of policies and programs and facilitate consideration of multiple perspectives in support of caregivers’ needs. A variety of usages for the lens were identified for both policies and programs that affect caregivers directly or indirectly including:

- Framing development of new programs and policies
- Designing policies and programs that value and support caregivers
- Critiquing proposed policies and programs for potential unintended negative effects
- Assessing whether policies or programs promote caregivers’ well-being
- Identifying gaps in current policies, programs and activities that affect caregivers
- Guiding studies of the impact of programs on caregivers
- Developing a policy response to an issue or need.

The Roundtable on Family Caregiving Advocacy and Action was a celebration of accomplishments and a call to action. Participants learned from each other and worked together to understand effective ways of advancing the agenda. It was agreed that there is an urgent need to continue the momentum with governments and as advocates we must truly seek to understand the government’s context and work within this reality.

Creating a future where Canada is the best in the world in meeting the needs of family caregivers requires the individual and collective efforts of many. All groups concurred that we must reach out and collectively share our knowledge to address the issues and challenges that are common to all caregivers as an important foundation to the customization that will occur within specialty groups, sectors and jurisdictions.

## Background

Home care is defined as “an array of services for people of all ages, provided in the home and community setting, that encompasses health promotion and teaching, curative intervention, end-of-life care, rehabilitation, support and maintenance, social adaptation and integration and support for the family caregiver.”<sup>i</sup>

Home care allows Canadians of all ages to recover or manage their health care issues in their home setting and *age in place* surrounded by family, friends and their community to which they can continue to make a meaningful contribution. It is these families and friends that are called upon to provide the necessary support at home, often at a personal health and/or financial toll. Family caregivers provide care and assistance 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>ii</sup> Recent research shows the imputed economic cost to replace family caregivers with the paid workforce at current market rates and usual employee benefits and support would be \$25 billion.<sup>iii</sup>

Recognizing the essential contribution of families, the Canadian Home Care Association (CHCA) has identified family caregiving as a strategic priority and is actively working with other partners to champion caregiver issues and influence policy direction. The CHCA is a signatory partner to the Canadian Caregiver Coalition (CCC) and the Executive Director serves as the Coalition president. CHCA and CCC believe that more needs to be done to recognize the role of the family caregiver and their significant contribution. Jointly and individually, along with many other organizations, associations, coalitions and networks, the momentum has been growing for the establishment of comprehensive relevant support for families in federal, provincial, territorial legislation. The elements of that support are reflected in a National Caregiver Strategy:

- Safeguard the health and wellbeing of family caregivers
- Minimize excessive financial burden placed on family caregivers
- Enable access to user friendly information and education
- Create flexible workplace environments that respect caregiving obligations
- Invest in research on family caregiving as a foundation for evidence-informed decision making

Governments recognize the importance of family caregivers, as evidenced by inclusion in policies at both the federal level (2011 throne speech and budget) and provincial level (caregiver specific legislation in Nova Scotia, Quebec and Manitoba).



In order to build on the momentum, a roundtable was convened to stimulate new ideas on the next steps for advocacy. Stakeholders with experience and knowledge in advocacy and government relations, particularly in the area of family caregivers, were brought together in order to imagine a future where Canada is the best in the world in meeting the needs of family caregivers.

## Approach

Thirty-five stakeholders were in attendance, representing a broad range of organizations including national associations, charities, coalitions, home care providers, employers, and government and caregiver coalitions from BC, Ontario and Quebec. A participant list is included in Appendix A. The diversity amongst the group resulted in a broad range of perspectives and experience and enriched the discussion.

The objectives for the meeting were to:

- Stimulate new ideas to ensure caregiver issues and solutions are included on federal / provincial / territorial discussions and planning tables.
- Identify innovative advocacy practices that contribute to the successful advancement of the caregiver agenda.
- Employ a unique “Caregiver Policy Lens” tool to align efforts and create consistent messages for collaborative actions and engagement at a policy – system – and front line level.

The 1 ½ day workshop was facilitated by **Nadine Henningsen** President of the Canadian Caregiver Coalition and Executive Director of the Canadian Home Care Association. Nadine provided an overview of the current state of caregiving in Canada and participants shared their experiences and updating each other with the successes and challenges within their context.

The agenda included an interactive morning session led by **Elizabeth Mulholland**, an independent public policy consultant, specializing in social development, sport for development, and innovation policy.

The afternoon session focused on the Caregiver Policy Lens, and was presented by **Penny McCourt**, Research Affiliate, Centre on Aging & Adjunct Professor, School of Social Work, University of Victoria and **Dawn Hemingway**, Associate Professor and Chair of the School of Social Work at the University of Northern British Columbia.

The Caregiver Policy Lens, developed at the British Columbia Psychogeriatric Association (BCPGA), is an analytical framework informed by literature and key informant interviews to assess planned and current programs and policies from the perspective of caregivers, and to identify any unintended negative effects on them.



# Strengthening Policy and Advocacy Impact

The meeting began with discussion about what governments need in order to move forward with policy recommendations and the pitfalls that advocates need to avoid. Drawing on her experience, the keynote speaker, Elizabeth Mulholland, described 'good policy' as *sound fiscal, tax, regulatory, programmatic and other policy advice that governments can feasibly implement without unwarranted political risk with reasonable confidence that it may yield the desired goal.*

The challenge for governments is an impatient electorate who want immediate change and outcome, often measured within a political term (4-5 years). As a consequence long-term strategies are often not considered because they are not rewarded during election time. Given this volatile and relatively short-term environment, governments often require the inclusion of a risk/benefit analysis in briefing reports in addition to policy recommendations and risk mitigation strategies that reflect short term investment and policy implementation.

Participants discussed strategies to avoid six common policy traps:

1. We care; government don't – advocates must resist stereotyping and work to better awareness
2. Identity versus impact – taking care not to pursue validation of the cause as we define it at the expense of good policy that works
3. Building on foregone conclusions – adopting an iterative, consultative, evidence-informed, learning process
4. Reality-free policy – the importance of assessing the environment and shaping your strategy accordingly
5. Apres-moi, le deluge - learning to “think like government” and factor in key considerations they must look at
6. Problems, problems, problems - embracing aspirational goals and advocating for solutions rather than problems.

Readers are directed to an article [Method Matters: How to Avoid Common Policy Traps](#).<sup>iv</sup>

## Elements of a National Caregiver Strategy

- Safeguard the health and wellbeing of family caregivers
- Minimize excessive financial burden placed on family caregivers
- Enable access to user friendly information and education
- Create flexible workplace environments that respect caregiving obligations
- Invest in research on family caregiving as a foundation for evidence-informed decision making



Participants worked in groups to examine three selected elements of the National Caregiver Strategy and generate practical actions steps applying the following methods for effective advocacy:

- Mapping the policy landscape
- Forging alliances and involving all sectors
- Building a common fact base
- Agreeing with government on the facts of the issue, its importance, and what to do about it
- Talking to government, listening, learning and adapting policy proposals.

## ***Discussion***

When considering the Caregiving Strategy element of **safeguarding caregiver health and wellbeing and increasing respite care**, participants identified a number of concrete strategies that would support policy advancements across Canada

- Clarify jurisdictional roles and responsibilities (i.e. federal / provincial / territorial) and stakeholder engagement (public, private sector).
- Define language and terminology (i.e. define health and wellbeing, family caregiver).
- Develop an inventory of common caregiver facts and research data to support advocacy messages.
- Leverage social media to test new ideas and keep people connected.
- Fund research to provide more baseline expenditure data related to current measures for family caregivers, through institutions such as the Canadian Institute of Health Research, should be undertaken.

**Access to user friendly information and education** is an important element within the Caregiver Strategy. There is a general sense that governments agree on the need to improve access to information and resources. Support for family caregivers is unquestionable and it transcends all interests groups. The challenge is in the nature of the action to be taken and coordination of the efforts to optimize outcomes and return on investment.

- A greater awareness and understanding of current support programs for family caregivers would be beneficial both for stakeholder groups and individual caregivers.
- Explore opportunities to leverage various communication methods (group support / internet / social networks etc).
- Sharing of caregiver issues across interest groups would enable common approaches to information resources and broaden the application and usage
- Build upon provincial initiatives such as the Caregiver Recognition Act introduced by the Manitoba government in June 2011.<sup>v</sup>

**Establishing flexible workplace environments** provides the opportunity for forging new alliances and broadening the sectors that support caregiver advocacy efforts. Natural allies include:

- Life & Health insurance benefits companies
- Small business
- Trade/professional associations
- Unions
- Employee assistance providers
- Human Resource Associations
- Sector councils – government groups
- Pension groups
- Banks – RBC, BMO
- Boards of Trade, Chamber of Commerce
- Imagine Canada
- Family Friendly Businesses
- Top employers

It is important to then ask new allies who else to invite to support the cause so that awareness continuously grows. Those that might not be aligned with this element of the Caregiver Strategy are small businesses that cannot afford additional costs and those who feel that government is too intrusive and should not be prescribing how flexibility in the workplace is achieved. Achieving common ground on this issue might be through facilitated dialogue to develop reasonable recommendations.

There is a reasonable amount of research on the needs of caregivers in the workplace and it was suggested that a central database of organizations / research be developed and shared.

# The Caregiver Policy Lens

The Caregiver Policy Lens is a framework for examining policies and programs from the perspective of caregivers. It can be used by policy makers and analysts, program managers, educators, service providers, researchers, caregiver advocates and organizations as a tool for analyzing government, organizational, program and service delivery policies.

The Caregiver Policy Lens is a series of questions intended to:

- Increase awareness about caregivers' needs.
- Facilitate the identification of any unintended negative effects of policies on caregivers.
- Promote the inclusion of the caregivers, both as partners in care and in the development, implementation and evaluation of policies and programs that affect them.

The Caregiver Policy Lens questions address:

- 1. Caregiver Involvement** - How are caregivers, caregiver advocates and caregiver organizations involved in the design/review of the policy, program or practice?
- 2. Collaboration** - Are relevant organizations, Ministries, interest groups and individuals concerned with caregiving involved?
- 3. Respect and Dignity** - Does the policy, program or practice reflect respect for caregivers and support their dignity through valuing the importance of their contribution and acknowledging their relationship with the care recipient?
- 4. Diversity and Marginalization** - Does the policy, program or practice assess whether diverse caregivers are likely to experience inequities or negative impacts resulting from their membership in marginalized groups?
- 5. Self-Determination and Independence** - Does the policy, program or practice promote and support caregivers' self-determination and independence?
- 6. Accessibility** - Does the policy, program or practice facilitate access to the services available to caregivers and make appropriate adaptations to accommodate diverse needs?
- 7. Responsiveness** - Is the policy, program or practice designed in such a way that crises and excess use of system supports are minimized?
- 8. Communication** - Are there clear lines of communication and responsibility between service providers and caregivers, and between agencies?
- 9. Resiliency** - Does the policy, program, or practice support the caregiver's capacity to cope with stress and adversity?
- 10. Individuality** - Are caregivers assessed for their own needs and addressed separately from the care recipient?
- 11. Sustaining Caregivers** - Does the policy, program, or practice help equip caregivers with knowledge, skills and respite to carry out their role?

## *Discussion*

Roundtable participants recognized the potential of the tool to ensure multi-sectoral consideration of policies and programs and facilitate consideration of multiple perspectives in support of caregivers' needs. Many volunteered to test the instrument.

The Caregiver Policy Lens can be used with policies and programs that affect caregivers directly or indirectly to:

- Frame development of new programs and policies
- Design policies and programs that value and support caregivers
- Critique proposed policies and programs for potential unintended negative effects
- Assess whether policies or programs promote caregivers' well-being
- Identify gaps in current policies, programs and activities that affect caregivers
- Guide studies of the impact of programs on caregivers
- Develop a policy response to an issue or need.

Educators can use the Caregiver Policy Lens to raise students' awareness, sensitivity and knowledge about the concerns and needs of caregivers. Advocacy groups can use the CGPL to critique policies and programs from the perspective of caregivers and to frame a response to policies and programs that affect caregivers.

The tool was seen as being useful to evaluate programs and establish consistency.

In addressing potential improvements, participants suggested that the Caregiver Policy Lens be modified to reflect Inuit, young caregivers, caregivers with a disability or illness, caregivers of adult children, and those fulfilling the caregiving responsibility from a distance.

The area of self determination provoked debate on caregivers' rights, not only to decline their level of involvement, but also to increase their caregiving role. In the mental health sector, caregivers and/or families can be excluded from the circle of care. Issues to be expanded upon in the Caregiver Policy Lens include abuse; caregiver 'smothering'; and the reality that caregivers are sometimes expected to perform tasks (i.e. at end-of-life) that are considered specialized skills even for professionals. The lens should also ensure that the benefits and rewards and strategies to mitigate negatives and enhance positives are addressed.

The concept of caregivers as consumers was explored. One participant reported that the average family caregiver in North America is a 48 year old female. We should be thinking about the services and products that this person wants and is prepared to pursue. Planning for caregivers requires policy makers and advocates considering the differing expectations across the generations.

Sustaining caregivers must be examined from the perspective of continuing with their lives – maintaining their employment, raising their children, and so on. It also reflects the requisite support in order to provide care – understandable, accessible and appropriate information.

## Commitments to Move Forward

Creating a future where Canada is the best in the world in meeting the needs of family caregivers requires the individual and collective efforts of many. Roundtable participants committed to a number of actions that include:

- Influencing Policy Direction
  - Compassionate Care Benefit enhancements, job protection, social supports
  - Use and promote the Caregiver Policy Lens
  - Increase connect with politicians
  - Understand and support the implementation of Manitoba's Caregiver Recognition Act
  - Establish supports for family caregivers in the 2014 FPT agreements for health and/or social transfers
- Broadening our Voice - Engaging Across Sectors
  - Reach out and involve employers
  - Convene roundtables to support sharing and collaboration
  - Leverage the value of coalitions to promote common messages and engage stakeholders
  - Connect staff across government departments – federal and provincial
- Increasing Awareness and Understanding
  - Highlight caregivers in national reports, address through the media
  - Reflect family caregivers in safety standards, home care teaching tools
  - Use social medias liberally and relentlessly to disseminate
- Directly Supporting Family Caregivers
  - Improve caregiver resources – written and electronic
  - Implement workplace programs to inform staff about the needs and importance of family caregivers

The Roundtable on Family Caregiving Advocacy and Action was a celebration of accomplishments and a call to action. There is much to be done if Canada is to be the best in the world in meeting the needs of family caregivers. Participants were able to learn from each other and work together to understand effective ways of advancing the agenda. There is an urgent need to continue the momentum with governments and as advocates we must truly seek to understand the government's context and work within this reality. We need to broaden our voice and build the caregiver movement beyond the currently engaged organizations. We need to increase understanding and share our knowledge to address the issues and challenges that are common to all caregivers as an important foundation to the customization that will occur within specialty groups, sectors and jurisdictions.

## *What if Canada was the best in the world in meeting the needs of family caregivers?*

We would live in a country that recognizes and respects the integral role of family caregivers in society and experience the following outcomes:

- 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.
- Financial measures are available that offset excessive caregiving expenses and support 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.
- Caregivers who must leave paid employment or curtail self-employed work in order to provide care can access job protection provisions and income support.
- 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.

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



<sup>i</sup> Canadian Home Care Association, [www.cdnhomecare.ca](http://www.cdnhomecare.ca)

<sup>ii</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>iii</sup> Hollander, M., Lui, G., Chappelle, N. (2009) Who Cares and How Much? *The imputed economic contribution to the Canadian healthcare system of middle-aged and older unpaid caregivers providing care to the elderly*. *Healthcare Quarterly*, 12(2) 2009: 42-49

<sup>iv</sup> Mulholland, E. (2011). Method Matters: How to Avoid Common Policy Traps. *The Philanthropist*. 23(4):481-488

<sup>v</sup> [web2.gov.mb.ca/bills/39-5/b042e.php](http://web2.gov.mb.ca/bills/39-5/b042e.php)

## Appendix A – Roundtable Participants

Alliance des Femmes de la Francophone Canadienne - Manon Beaulieu, Director General

Advocacy School - Sean Moore, Founder and Principal of Advocacy School

Alzheimer Society of Canada - Eric Lamoureux, Director of Public Policy and Government Relations,

BC Psychogeriatric Association - Dr. Penny McCourt, Founding Member

BC Psychogeriatric Association - Dawn Hemingway, Past President

Caledon Institute of Social Policy - Sherri Torjman, Vice President

Canadian Cancer Society - Denise Page, Senior Health Policy Analyst

Canadian Caregiver Coalition - Marg, McAlister, Consultant

Canadian Home Care Association - Nadine Henningsen, President & Signatory Partner Canadian Caregiver Coalition

Canadian Red Cross - Maxine Jackman, Deputy General Manager / Senior Director Community Health Services

Caregiver Omnimedia Inc - Don Fenn, President and Founder

CSA Standards - Jeanne Bank, Manager, Standards, Health Care and Safety

Family Caregivers' Network Society (BC) - Barb MacLean, Executive Director

First Nations and Inuit Home and Community Care Program - Jennifer Greene, Senior Policy Advisor

Health Canada - Julie Carver, Policy Analyst, Chronic and Continuing Care Division, Strategic Policy Branch

Health Charities Coalition of Canada - Deirdre Freiheit, Executive Director

Health Council of Canada - Shilpi Majumder, Policy Lead Analysis and Reporting

Health Council of Canada - Karen Hunter, U of T HPME student

J. W. McConnell Family Foundation - Dana Vocisano, Senior Program Officer

Manitoba Caregiver Coalition - Julie Donaldson, Spokesperson

Manitoba Caregiver Coalition - Wendy Sutton, Strategic Planning

Mental Health Commission of Canada - Ella Amir, Chair Family Caregiver Committee

Mulholland Consulting - Elizabeth Mulholland Principal

Multiple Sclerosis Society of Canada - Kim Steele, Manager, President's Office and Strategic Initiatives

Neurological Health Charities Canada - Shannon MacDonald, Director, Policy & Partnerships

Ontario Caregiver Coalition - Lisa Levin, Vice President, Home Services & Strategic Development, Circle of Care

Patient's Association of Canada - Kathy Kastner, Editor and Curator [www.Ability4Life.com](http://www.Ability4Life.com)

Quality End of Life Care Coalition of Canada - Sharon Baxter, Executive Director, Canadian Hospice Palliative Care Association

RANQ - Marilyn Krelenbaum, Spokesperson RANQ, President of the English Caregiver Coalition of Montreal (ECCOM)

Revera - Janet Ko, Signatory Partner Canadian Caregiver Coalition

Revera - Trish Barbato, Senior Vice President, Home Health and Business Development

Saint Elizabeth Health Care - Nicole Beben, Signatory Partner Canadian Caregiver Coalition

Saint Elizabeth Health Care - Louise Murray, Director of Charitable Programs and Events

VON Canada - Bonnie Schroeder, Signatory Partner Canadian Caregiver Coalition

We Care Home Health Services - Jamie Sutherland, Director of Marketing & Business Development



Canadian Home Care  
Association  
canadienne de soins  
et services à domicile

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