



# Mobilizing Action

## INTEGRATED ACTION PLAN

Final Report April 2016

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



**Mobilizing Action**  
Family Caregivers in Canada  
**Mobiliser l'action**  
Les proches aidants au Canada

# BACKGROUND

## THE CONCEPTION OF MOBILIZING ACTION

*Mobilizing Action: Family Caregivers in Canada* is a two year funded project (April 2014- March 2016) sets out to develop concrete action plan that will better support Canadian carers, also known as family caregivers. The catalyst of and frame for this pan-Canadian project evolve from a number of seminal reports: the 2011 *Canadian Caregiver Strategy*, the 2013 Action Table on Family Caregivers and the 2013 The Way Forward Caregiver Consultations. Through a collaborative model of engagement, the project aims to develop a blueprint of tangible actions that will influence future policy directions and areas of action that address the physical, psychosocial and financial needs of carers.

Specifically, actions that will:

- 1. Enhance awareness** of caregiver needs and facilitate their voice in care provision and the health care system.
- 2. Improve access** to caregiver support services and patient care resources
- 3. Alleviate financial burden** placed on family caregivers
- 4. Create supportive workplaces** that recognize caregiving obligations

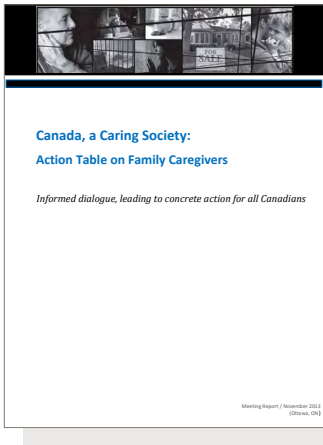
The project is made possible through the initiation of the Canadian Cancer Action Network (CCAN)<sup>1</sup> in partnership with the Canadian Home Care Association (CHCA) and Carers Canada (formerly known as Canadian Caregiver Coalition).

Activities of Mobilizing Action are grounded by the following core principles:

- Collaborative engagement
- Active involvement of family caregivers
- Credible leadership
- Individual and collective accountability
- Dynamic communication
- Intentional and audacious

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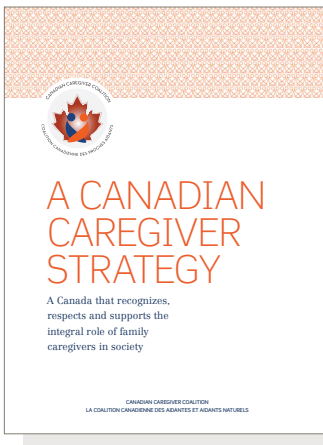
<sup>1</sup> Production of this publication has been made possible through financial support from the Canadian Partnership Against Cancer and Health Canada. The views expressed herein represents the views of the Canadian Cancer Action Network and do not necessarily represent the views of Health Canada.



## Canada, A Caring Society: Action Table on Family Caregivers

Funded by the Canadian Partnership Against Cancer, this consultation was led by the Canadian Cancer Action Network in partnership with the Canadian Cancer Society, the Canadian Caregiver Coalition, and the Mental Health Commission of Canada. Over 40 stakeholders and caregivers from across Canada provided their insight to the development of concrete solutions aimed at reducing the financial hardship faced by family caregivers. The output of the action table highlighted four shared themes, namely: enhanced awareness, improved access to resources, flexible workplace, and better understanding of government programs.

<http://www.cccanceraction.ca/wp-content/uploads/2014/12/Family-Caregivers-Meeting-Report.pdf>



## Canadian Caregiver Strategy

Developed through extensive consultations with family caregivers across Canada, the Canadian Caregiver Strategy describes how Canada can address the priorities of family caregivers and the role of governments, organizations and individuals in the implementation of the strategy. Released in 2009 and updated in 2013 by the Canadian Caregiver Coalition, the strategy outlines five priorities:

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

[http://www.carerscanada.ca/wp-content/uploads/2016/01/CCC-Strategy-Renewal\\_web-pages.pdf](http://www.carerscanada.ca/wp-content/uploads/2016/01/CCC-Strategy-Renewal_web-pages.pdf)

## **ABOUT CANADIAN CARERS**

Over one quarter, or 8.1 million of Canadians are carers. Also referred to as a caregiver or family caregiver, a carer 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. Research consistently estimates between 70 and 80 percent of the care given in the community to older adults is provided by family and friends. Carers are the hidden backbone of our health care system, contributing over 25 billion dollars annually of unpaid labour.

Caregiving can include wide array of helping activities, varying levels of intensity and degree of physical and emotional demands on the caregivers. They provide wide array of activities, including household works, personal and medical care, financial management, transportation and social supports. Carers have multiple responsibilities beyond caring for their chronically ill, disabled or aging family member or friend. Over one quarter of carers are sandwiched between child rearing, caregiving, and paid work. In fact, carers represent more than 35 percent of the Canadian workforce, with the majority in their peak earning years.

Therefore, although caregiving can be a meaningful experience, it is certainly not without a cost. Family caregivers can experience negative effects on their physical, financial and psychosocial well-being as a result of their caring role. The financial impacts related to caring for loved one can be significant. In 2012, 1.6 million caregivers took leave from work; nearly 600,000 reduced their work hours; 160,000 turned down paid employment; and 390,000 had quit their jobs to provide care. This is equivalent to \$1.3 billion in lost productivity per year. Additionally, carers often have to incurred extra expenses due to their caregiving responsibilities. Collectively, Canadian caregivers aged 45 and older spent approximately \$1,049,600 per month on care-related out of pocket expenditures in 2006, or almost \$12.6 million.

Early research suggests that caregiving can be beneficial when carers are supported: providing care for others can enhance social and emotional development, build a sense of competence and self-efficacy, and nurture empathy and compassion. However without adequate support, it is simply unrealistic to expect carers to continue ensuring the quality of life, social engagement and stability to those they provide care even if they want to.

## Collaborative Model of Engagement

Drawing on the CCAN Collaborative Model of Engagement, all activities within the Mobilizing Action project are undertaken in partnership with key stakeholders in order to share resources, avoid duplication and mobilize action.

### **LEADERSHIP AND ORGANIZATIONAL SUPPORT**

This multi-stakeholder initiative is guided by a National Steering Committee (NSC) whom provide their expertise to plan, explore options, make decisions and implement activities relevant to project deliverables and outcomes. Members of the NSC include: 3M, Canadian Cancer Action Network, Canadian Home Care Association, Canadian Human Rights Commission, Canadian Partnership Against Cancer, Carers Canada, Janssen Inc., Mental Health Commission of Canada, Saint Elizabeth and SEIU Healthcare.

### **CAREGIVERS ENGAGEMENT**

Engaging caregivers is an integral component to the success of Mobilizing Action. Guided by the project consultant team, the Caregiver Advisory Group (CAG) serves in an advisory capacity by embedding a unique caregiver and/or patient lens at critical points in the project. The CAG lent their voice and experience to ensure the activities and outcomes of the plan align with realities of caregiving. Members of CAG include: Odette Beaudoin, Helene Hardy, Barbara Morgan, Lorna Scott and Lori Taraba.

### **A COLLABORATIVE AND MULTI-JURISDICTIONAL APPROACH**

The Mobilizing Action team undertook a series of consultations to engage diverse stakeholders in developing a detailed plan that will mobilize broader action in supporting carers. Two events, in September and November 2014, brought experts together to identify action points that address the four key priorities: awareness, financial, access, and workplaces. The Mobilizing Action: Integrated Action Plan was developed through these extensive consultations and endorsed by a broad range of caregivers, health care professionals and employers that makes up the caregiver networks, researchers, government bodies, community support groups and non-governmental organizations, and labour representatives.



- 1 CAREGIVER NETWORK

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- 1 GOVERNMENT

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- 3 PHARMACEUTICAL COMPANIES

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- 20 SERVICE PROVIDERS/NGOS

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- 1 LABOUR REPRESENTATIVE

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# Processes: Engagement, Priority Setting and Consensus Building

## PRIORITY SETTING: 2-DAY ACTION PLANNING ROUNDTABLE

60 diverse stakeholders convened in Toronto for a two-day action planning roundtable on September 22-23, 2014. The roundtable consisted of three key activities:

### 1. CURRENT REALITIES OF CAREGIVING IN CANADA

The roundtable began with two presentations by carers. The caregivers described their caring experiences – blessings and challenges – to ensure the dignity and quality of life of the person they cared for. Featuring the caregiver voice at the start of the two-day event personalized the issues for participants who may not be able to identify themselves as a carer. However, interestingly, participant introductions revealed that although individuals were there to represent their organization or stakeholder group, the majority of participants recognized and shared their experiences as a caregiver.

### 1. SYNERGIES ACROSS THE COUNTRY

Panel presenters during the roundtable were progressive in nature and took participants through the three phases in taking their vision to action. The discussion took place before the participants engaged in the working groups and helped frame the discussion and stimulate conversation. The panel sessions illustrated the progress that has been made and what is yet to be done to better support Canadian carers.

The first panelists addressed the question “What Do We Know?” and featured representatives from Carers Canada, the Canadian Human Rights Commission, the Canadian Cancer Action Network and The Way Forward. Each group provided a snapshot of their projects and shared the progress to date on advancing the needs of caregivers in Canada. Specific activities included the development of a *Canadian Caregiver Strategy* (the identification of carers’ needs and prioritization of these into key themes), the needs of employed caregivers and initiatives to support caregiving as a human right, and the unique needs of caregivers during end-of-life care.

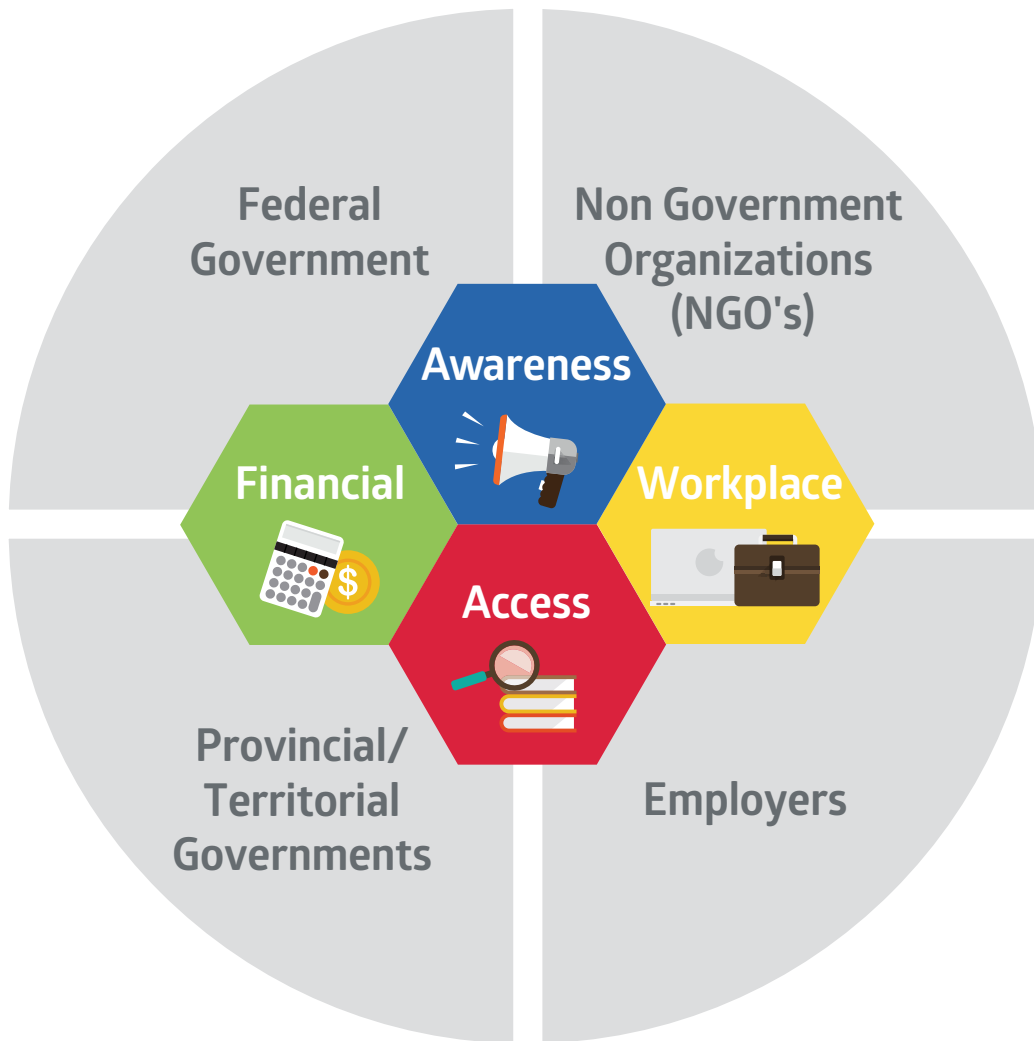
The second panel session explored the question “What Can We Accomplish?” Participants discussed areas of growth and inspiration to advance the needs of carers. This panel featured Dr. Janet Fast, a leading researcher of the economic implications of caregiving in Canada; Lorna Scott, a caregiver who supported her husband throughout his palliative care journey, wrote a book on her experience and now coaches other caregivers; and Vickie Cammack, a social entrepreneur in the area of caregiving and an expert advisor for the Canadian Employers for Caregivers Plan. Resonating points from this panel included:

- Converting the skeptics and normalizing caregiving as an integral part of human experience;
- How do “we” become “us,” beyond our role as a caregiver;
- The positive effect a flexible workplace can have on the care journey; and
- The importance of innovative solutions, creative problem solving and a marketing campaign in creating a caregiver strategy.

The final panel session explored “What Can We Leverage?” and provided a platform for members of provincial caregiver groups to share their successes and challenges. Panelists included members from the Family Caregivers of British Columbia; the Alberta Caregivers Association; the Manitoba Caregiver Coalition; the Ontario Caregiver Coalition; Quebec’s Centre de santé et de services sociaux Cavendish; and the Caregivers Nova Scotia association. This panel provided many promising innovative approaches to support carers that are currently in the planning and operational phases across the country.

### 3. FACILITATED ACTION PLANNING WORKING GROUPS

A series of working groups took place during the roundtable to (1) expand on the issues identified during the caregiver consultations from the viewpoints of different stakeholders; and (2) identify strategic actions and priorities to address carer needs. The working group participants were challenged to contextualize their thoughts through different stakeholder perspectives: the federal government; provincial and territorial governments; local networks, non-government organizations and service providers; employers; and family caregivers. The interactive discussions resulted in broad commitment to specific objectives, goals and actions targeted to stakeholder groups. Participants in the working groups included family caregivers, health professionals, service providers, community support groups, researchers, public servants, non-government organizations, employers and a labour representative. The actions that emerged from the roundtable echoed previously-identified caregiver needs and provided a multi-dimensional plan to address family caregivers and end-of-life care.





## CONSENSUS BUILDING: E-DELPHI CONSULTATION

The Delphi technique is designed as a group communication process which aim to achieve a convergence of opinion on an issue from a group of diverse experts. It is an electronic discussion that are carried out by email over a period of approximately 30 days. It is an iterative process, normally two to three rounds, involving a series of questionnaires, each building on the results of the previous one.

Between January – February, two rounds of E-Delphi consultation were conducted to achieve the following objectives:

- Reach agreement on the Mobilizing Action: Integrated Action Plan that emerged from the discussions of the September action table.
- Ensure any proposed strategies and actions are specific, measurable, achievable, relevant and timely.
- Identify current initiatives that can be leveraged to advance proposed strategies/actions
- Determine stakeholders' level of collaboration in advancing the objectives forward

Participants of E-Delphi were the same as those for the Action Planning Round Table.

### ROUND 1 OF E-DELPHI:

A draft action plan was shared with participants, which includes priorities, objectives, tactics and indicators of success for the four identified themes in supporting carers: awareness, access, financial burden and flexible workplace. This plan incorporates the suggestions and recommendations that emerged from stakeholders in the September 2014 Action Planning Roundtable.

The participants were given 2 weeks to provide their response and comments for 4 questions for each objectives and strategic priorities that we have identified:

- Is the objective realistic?
- Are the strategic goals achievable?
- Is this a priority for you / your organization?
- How involved can you be?

### ROUND 2 OF E-DELPHI:

The objectives and strategic goals have been modified based on the feedback received from the first round of E-Delphi. The action plan is now categorized by the target audience, rather than key elements, and are ordered by level of priority. This is in recognition of the different level of priorities and scope of influence identified by the respondents. All responses were shared anonymously so that participants saw overall trends but no one knew who wrote which specific responses. A set of questions was once again developed to identify current initiatives that can be leveraged and determine stakeholders' level of collaboration in advancing the action plan. The following questions were then given to participants:

#### 1. How will you collaborate?

NONE (This is not a priority for my organization)

LOW (Keep me informed and I will share activities with my stakeholders)

MEDIUM (I have information/research that I can share)

HIGH (I want to be involved in a working group)

#### 2. For those who selected "high" level of collaboration, how involved can you be?

LOW (Share expertise)

MEDIUM (Provide in-kind resources)

HIGH (Provide in-kind and financial resources)

DON'T KNOW

Through these extensive consultations, Mobilizing Action: Integrated Action Plan is developed.

## Outcomes

Within two years, *Mobilizing Action: Family Caregivers in Canada* established collaborative approach in order to build a foundation for shared action. Appendix A provides a summary of Mobilizing Action's achievements which include:

- The implementation of a multi-stakeholder National Steering Committee and a Caregivers Advisory Group to inform and provide leadership to the project
- Primary research to uncover core gaps in caregiver supports in Canada
- Visual branding and communication tools to promote successes and opportunities within the project as a collaborative initiative
- Deliberative engagement (two-day action planning workshop) to shape core objectives, determine priorities and define strategies
- National E-Delphi consultation in order to co-create a blueprint for integrated action in support of carers leading to the production of the first Integrated Action Plan for Carers in Canada

# 1. INTEGRATED, MULTI-STAKEHOLDER ACTION PLAN

In 2014-2015, the project focused on achieving stakeholder engagement and consensus in order to mobilize integrated action in key priority areas. Serving as a blueprint for coordinated actions to support carers, the Integrated Action Plan was produced to advance mutual priorities and objectives by targeting specific stakeholders and leveraging their sphere of influence.

## TOGETHER WE MAKE CHANGE HAPPEN

### Our Shared Outcomes and Indicators of Success

OUTCOMES	INDICATORS OF SUCCESS
<p>Together, we will enhance awareness of caregiver needs and facilitate their voice in care provision and the health care system.</p> <ul style="list-style-type: none"> <li>Family caregivers are recognized for their contributions to the health and well-being of Canadians, the sustainability of our health care system and the viability of our economy.</li> <li>Caregivers' unique needs are consistently identified and addressed in government policies and programs.</li> <li>Family caregivers are actively consulted and engaged in health system planning and delivery.</li> </ul>	<p><b>We have achieved success when:</b></p> <ol style="list-style-type: none"> <li>Family caregivers are recognized in the federal government's throne speech and are included in national health and social strategies.</li> <li>The Prime Minister proclaims the value of family caregivers on National Caregiver Day (the first Tuesday in April).</li> <li>The Provinces and Territories identify caregivers as a critical element in their action plan for seniors.</li> <li>Non-governmental organizations (NGOs) recognize family caregivers in their awareness, education and advocacy campaigns.</li> <li>Family caregivers are included in health care planning processes.</li> <li>The province of Ontario designates a caregiver day or week.</li> </ol>
<p>Together, we will improve access to caregiver support services and patient care resources.</p> <ul style="list-style-type: none"> <li>Family caregivers have access to information and support services that address their unique needs.</li> </ul>	<p><b>We have achieved success when:</b></p> <ol style="list-style-type: none"> <li>Technology applications are available to support caregivers' needs.</li> <li>Provider organizations have tools to support health care professionals in recognizing patient – family caregiver dyad and the unique needs of caregivers.</li> <li>A "hub &amp; spoke" model for accessing on-line caregiver resources (linking local and national sites) is developed and tested.</li> </ol>
<p>Together, we will alleviate the financial burden placed on family caregivers.</p> <ul style="list-style-type: none"> <li>Family caregivers have access to the appropriate resources that alleviate the financial burden associated with providing care.</li> </ul>	<p><b>We have achieved success when:</b></p> <ol style="list-style-type: none"> <li>Provinces pilot and evaluate flexible funding models for home care services and community supports.</li> <li>The Compassionate Care Benefit and Family Caregiver Tax Credit eligibility is enhanced to meet the myriad of caregiver situations.</li> </ol>
<p>Together, we will create supportive workplaces that recognize caregiving obligations.</p> <ul style="list-style-type: none"> <li>Canadian employers have supportive workplace policies and programs that recognize and respect caregiver obligations.</li> <li>The caring experience is valued and recognized as an employment asset.</li> </ul>	<p><b>We have achieved success when:</b></p> <ol style="list-style-type: none"> <li>10 employers are recognized for their innovative HR strategies in supporting employee caregivers.</li> <li>Employers have access to tools and resources to support their employee caregivers.</li> <li>The federal government develops new approaches to support employed and employable family caregivers to remain in the workforce.</li> </ol>

## MUTUAL PRIORITIES AND OBJECTIVES

### Together, we will ENHANCE AWARENESS of caregiver needs and facilitate their voice in care provision and the health care system

PRIORITIES	OBJECTIVES
<p><b>CAREGIVER AWARENESS</b></p> <p>Family caregivers are recognized for their contributions to the health and well-being of Canadians, the sustainability of our health care system and the viability of our economy.</p>	<p><b>ACTING TODAY – MOBILIZING ACTION’S PRIORITIES:</b></p> <p>Federal political parties will include specific actions for family caregivers as part of their 2015 election plans.</p> <p>The Prime Minister will issue a proclamation recognizing the diversity, role and value of family caregivers on National Caregiver Day (the First Tuesday in April), April 4, 2017.</p> <p><b>ENVISIONING THE FUTURE – MOBILIZING ACTION’S PROPOSED ACTIONS:</b></p> <p>Ontario will designate the first Tuesday in April as a caregiver recognition day in 2016.</p> <p>10 national patient disease groups will include caregiver support programs as part of their educational offering by 2016.</p> <p>The provinces and territories will identify family caregivers as a key element in their joint recommendations for a seniors strategy by 2016.</p> <p>NGOs and service providers will have access to best practices in facilitating the voice of caregivers.</p>
<p><b>CAREGIVER MANIFESTO</b></p> <p>Caregivers’ unique needs are consistently identified and addressed in government policies and programs.</p>	
<p><b>CAREGIVER EXPERIENCE</b></p> <p>Family caregivers are actively consulted and engaged in care delivery and health system planning.</p>	

### Together, we will IMPROVE ACCESS to caregiver support services and patient care resources

PRIORITIES	OBJECTIVES
<p><b>USER FRIENDLY INFORMATION</b></p> <p>Family caregivers know about and easily access services and information when and as they are needed.</p>	<p><b>ACTING TODAY – MOBILIZING ACTION’S PRIORITY:</b></p> <p>Provincial/territorial governments identify technology applications that support family caregivers by 2017.</p> <p><b>ENVISIONING THE FUTURE – MOBILIZING ACTION’S PROPOSED ACTIONS:</b></p> <p>Health care providers will have access to resources to recognize and support caregivers by 2017.</p> <p>One provincial government will examine the structure and viability of a navigation/information system that uses a hub and spoke approach by 2016.</p>
<p><b>TECHNOLOGY-ENABLED ACCESS</b></p> <p>User friendly technology is available to support caregivers’ needs.</p>	
<p><b>SYSTEM NAVIGATION</b></p> <p>Health care professionals support caregivers with information and resources to navigate the health and social care systems.</p>	

### Together, we will create SUPPORTIVE WORKPLACES that recognize caregiving obligations

PRIORITIES	OBJECTIVES
<p><b>CAREGIVER FRIENDLY WORKPLACES</b></p> <p>Caring experience is valued and recognized in employment policies and programs.</p>	<p><b>ACTING TODAY – MOBILIZING ACTION’S PRIORITY:</b></p> <p>Starting in 2016, targeted employers will recognize and include working caregivers in their human resource strategies.</p> <p><b>ENVISIONING THE FUTURE – MOBILIZING ACTION’S PROPOSED ACTION:</b></p> <p>The federal government will support a consultation on strategies to implement corporate tax incentives for employers by 2016.</p>

## 2. MOBILIZING ACTION TEAMS

Year one of this project has exceeded our expectations. The support and commitment we have received throughout our consultation and engagement process has been overwhelmingly positive. To build on this momentum, the Steering Committee agreed to expand the project scope and initiate a select number of actions immediately.

From late 2015 to the conclusion of project funding, efforts to further define stakeholder mapping and engagement continue. A total of 48 stakeholders, including caregivers, involved in 4 Mobilizing Action Teams to further align efforts, share expertise and develop specific work plans to advance four key objectives – one for each of the four priority areas. Specifically, functions of the Mobilizing Action Teams include:

- Develop, implement and evaluate an action plan to advance the priority objective.
- Identify resource requirements and funding opportunities to ensure advancement of the collaborative work place. Members are encouraged to consider funding and in-kind contributions.
- Share progress toward the objective within the MAT and with the national Steering Committee

To promote continuity, the Chair/Co-Chair positions were held by a representative of one of the National Steering Committee members. The chair functioned as a facilitation for the working group and act as the spokesperson for the Mobilizing Action Team.

Appendix B provides a summary of Mobilizing Action Teams achievements and recommended future plan.

### **AWARENESS MOBILIZING ACTION TEAM**

Mobilizing Action Team that led and undertook the execution of tactics to advance awareness for carers by achieving the following objectives of the Integrated Action Plan:

- Federal political parties will include specific actions for family caregivers as part of their 2015 election plans.
- The Prime Minister will issue a proclamation recognizing the diversity, role, and value of family caregivers on National Caregiver Day (the first Tuesday in April), April 4, 2017.

Members of the Awareness of Mobilizing Action Team include:

- Carers Canada
- Canadian Home Care Association
- Canadian Nurses Association
- Canadian Hospice Palliative Care Association
- Health Charities Coalition of Canada
- Helene Hardy, Caregiver
- Home Instead Senior Care
- Janssen Inc.
- Lorna Scott, Caregiver
- Multiple Sclerosis Society of Canada
- Parkinson Society of Canada
- SEIU Health Care

During its 7 months term, the Awareness MAT served as a catalyst to connect, support and influence multi-stakeholders in raising their voice on behalf of carers. A total of 7 meetings were held by teleconference.

**OBJECTIVE 1A. Federal political parties will include specific actions for carers as part of their 2015 election action plans**

ACTIVITIES:

- Alignment of key messages and ‘asks’ with diverse organizations:
  - Financial Support
  - Health and Well-being
  - Supportive workplaces
- Identification and alignment of federal party positions on caregiving issues
- Supporting election strategies that were underway:
  - Canadian Nurses Association – Series of community town halls “Health is where the Home is”
  - Canadian Medical Association – Thunderclap Campaign - Demand a Plan
  - College of Family Physicians of Canada
  - National Senior Strategy
  - Parkinson Society of Canada’s National Ambassador
- Leveraging social media to strengthen our voice and shape federal leaders’ debate: engage caregivers, national NGOs, and other active coalitions to raise their voice on the importance of carers:
  - Globe & Mail, in partnership with Google Canada and Cable Public Affairs Channel, Leaders’ Debate “Our Economy. Our Future”
  - TVA French-language leaders’ debate

OUTPUTS/OUTCOMES:

- 3 Ministerial Mandate Letters outlines caregiver initiative
  - Minister of Health
  - Minister of Families, Children and Social Development
  - Minister of Employment, Workforce Development and Labour

**OBJECTIVE 1B. The Prime Minister will issue a proclamation recognizing the diversity, role and value of carers on National Carers Day (the first Tuesday in April), April 4, 2017**

ACTIVITIES:

- Building on 2015 Election Result, consulted with a government relations group to gain analysis of the election: what it means to us and strategic advice on future direction
- Identify potential caucus member as carers champions
- Develop Carers Brief outlining issues, facts, asks, and returns on investment

OUTPUTS/OUTCOMES:

- Carers Advocacy Brief (See Appendix C)
- Recommendations – Carers Champions (See Appendix D)

## **ACCESS MOBILIZING ACTION TEAM**

Mobilizing Action Team that led and undertook the execution of tactics to improve access to caregiver support services and patient care resources for carers by achieving the following objective:

- Provincial/territorial governments identify technology applications that support carers

Members of the Awareness of Mobilizing Action Team include:

- Carers Canada
- Canadian Cancer Action Network
- Canadian Home Care Association
- Canadian Hospice Palliative Care Association
- CareLink Advantage
- Canadian Virtual Hospice
- Memorial University – Centre for Nursing Studies
- GE Healthcare
- Philips Lifeline Canada
- Vickie Cammack, consultant

During its 5 months term, the Access Mobilizing Action Team focused on technology-enabled carers in Canada. They are carers who are empowered and connected through the innovative use of technology. A total of 2 meetings were held by teleconference.

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### **OBJECTIVE. Provincial/territorial governments identify technology applications that support carers**

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ACTIVITIES:

- Construction of the Business Case for Technology Enabled Carers, outlining caregiver needs and outcomes
- Setting the frame for a Caregiver Survey to understand carers' receptivity to technology, types of technologies that are attractive to technology-using families, and factors influencing the use of technology
- Development of Action Plan template to set direction and further mobilize Access' objective post-funding

OUTPUTS/OUTCOMES:

- Building the Case for Technology Enabled Carers (Appendix E)
- Making Change Happen – Action Plan – Technology Enabled Carers (Appendix F)

## **FINANCIAL MOBILIZING ACTION TEAM**

Mobilizing Action Team that led and undertook the execution of tactics to alleviate the financial burden placed on carers by achieving the following objective:

- Provincial/territorial governments will explore a variety of funding options to support home care and long-term care services to relieve carer burdens starting in 2016.

Members of the Financial Mobilizing Action Team include:

- Alberta Caregivers Association
- Alberta Health Services
- Care at Home
- Carers Canada
- Canadian Home Care Association
- CBI Health Group
- Closing the Gap
- Nursing and Homemakers Inc. (NHI)
- Ontario Caregiver Coalition
- Pam King, Chair Caregiver Advisory Group
- PEI Health
- SEIU Health Care

During its 5 months term, the Financial Mobilizing Action Team focused on the correlation between insufficient home care funding and respite care in Canada. A total of 2 meetings were also held by teleconference.

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**OBJECTIVE. Provincial/territorial governments will explore a variety of funding options to support home care and long-term care services to relieve carers burden starting in 2016**

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ACTIVITIES:

- Develop a parameter and approach to constructing a comprehensive national briefing paper on respite options to provide “a break/time off/relief” for carers
- Set out action plan to further advance objective in bringing affordable respite services for carers

OUTPUTS/OUTCOMES:

- Scope of Briefing Paper for Respite as an Outcome (Appendix G)

**SUPPORTIVE WORKPLACE MOBILIZING ACTION TEAM**

Mobilizing Action Team that led and undertook the execution of tactics to advance supportive workplaces for carers by achieving the following objective:

- Targeted employers will recognize and include working carers in their human resources strategies.

Members of the Awareness of Mobilizing Action Team include:

- CBI Health Group
- Carers Canada
- Canadian Home Care Association
- Canadian Human Rights Commission
- Janssen Inc.
- Mental Health Commission of Canada
- McMaster University/ CIHR
- Saint Elizabeth
- Vanier Institute of the Family
- Vickie Cammack, Consultant
- University of Guelph, Dr. Donna Lero

During its 5 months term, the Workplace Mobilizing Action Team focused in connecting and mobilizing current initiatives that advance caregiver-friendly workplace environments. A total of 2 consultations were held, teleconference and online.

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**OBJECTIVE. Provincial/territorial governments identify technology applications that support carers**

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ACTIVITIES:

- Built awareness of working carers and the business benefits of supportive workplace environments through an engagement campaign that builds upon Carers Canada’s Work & Care: A Balancing Act initiative
- Initiated a Caregiver-Friendly Workplace Standard through participation and support of Dr. Allison Williams, McMaster University, and Canadian Standards Association proposal to the CIHR/SSHRC Health and Productive Work Grant
- Conducted online consultation to obtain the input of the Supportive Workplace Mobilizing Action Team members on key messages, target audience and potential vehicles/platforms to effectively deliver key messages

OUTPUTS/OUTCOMES:

- Online Consultation Result: Communication and Engagement Recommendations (Appendix H)



## Envisioning the Future

In realizing actions for carers, Mobilizing Action proposes a multi-year blueprint to guide future strategies to better support carers. The initial work by Mobilizing Action Teams, along with the additional Strategic Directions laid out in the Integrated Action Plan, lay out well-defined long-term, immediate strategies and practical actions for all levels of government, non-governmental organizations, businesses and individuals to improve the lives of carers. Furthermore, this phase of the project has established collaborative approach, linkages and synergistic partnerships, to build a foundation for shared action. On behalf of Mobilizing Action: Family Caregivers in Canada, we are humbled to have received the commitment of diverse organizations and stakeholders across the nation to realize a Canada that recognizes, respects and supports the integral role of carers in society.

Phase II of this project can lead to a measurable increase in the collaboration of civil society organizations, agencies and government to support carers in Canada. The impact is expected to result in a greater ability to inform, influence and impact healthcare system priorities amongst federal, provincial and territorial governments, as well as other health care policy makers, service providers, patients and carers.

We hope *Mobilizing Action: Family Caregivers in Canada* will empower stakeholders to advance key actions within their scope of influence and ignite joint commitment between government and stakeholders in keeping the action plan vibrant.

# APPENDIX A. Mobilizing Action Family Caregivers in Canada Achievements and Milestones (at-a-glance)



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Les proches aidants au Canada

## Outcome Report

**MOBILIZING ACTION: FAMILY CAREGIVERS IN CANADA IS A TWO YEAR PROJECT (APRIL 2014- MARCH 2016) DESIGNED TO:**

1. Develop an Action Plan to influence future policy directions and programming to supporting family caregivers.
2. Broaden awareness of caregiver needs and understanding of the Action Plan through integrated communication strategies.

### NATIONAL STEERING COMMITTEE:

3M

- Canadian Cancer Action Network
- Canadian Home Care Association
- Canadian Human Rights Commission,
- Canadian Partnership Against Cancer
- Carers Canada
- Janssen Inc.
- Mental Health Commission of Canada
- Saint Elizabeth
- SEIU Healthcare

### CAREGIVER ADVISORY GROUP:

- Odette Beaudoin
- Helene Hardy
- Barbara Morgan
- Lorna Scott
- Lori Taraba

### PROJECT FUNDERS:



### NOTABLE MOMENTS FOR MOBILIZING ACTION: DEFINING THE ACTION PLAN

#### SETTING THE STAGE

- 2011** ..... ○ **A CARERS MANIFESTO:** Carers Canada outlines priorities identified by carers and organizations that support them, releases *Canadian Caregiver Strategy*.
- 2013** ..... ○ **ACTION TABLE ON FAMILY CAREGIVERS:** Canadian Cancer Action Network convenes over 40 stakeholders and caregivers identify solutions to reduce the financial hardships faced by family caregivers.
- THE WAY FORWARD CAREGIVER CONSULTATIONS:** Caregivers identify their needs in caring for someone with a life-limiting illness.

#### SHAPING THE VISION

- APR 2014** ..... ○ **MOBILIZING ACTION:** Launch of the coordinated initiative *Family Caregivers in Canada*.

#### LEADERSHIP AND DIRECTION

**EXPERT OVERSIGHT:** Formation of *National Steering Committee* and *Caregiver Advisory Group*.

#### COLLABORATIVE ENGAGEMENT

- SEPT 2014** ..... ○ **ACTION PLANNING ROUNDTABLE:** Over 50 stakeholders come together for 2 days to identify specific actions for governments, employers and health providers to support carers.
- JAN - FEB 2015** ..... ○ **E-DELPHI CONSULTATION:** Interactive discussions to reach consensus on and endorsement of the *Action Plan*.

#### ARTICULATING THE PLAN

- JUN 2015** ..... ○ **INTEGRATED AND SHARED ACTION PLAN:** a blueprint for coordinated actions to support carers. The *Action Plan* contains 7 strategic outcomes and 14 measurable indicators to support the achievement of 13 clear objectives and 92 recommended actions.

#### MOBILIZING ACTION

- AUG 2015** ..... ○ **ENHANCED PROJECT SCOPE:** Coalesce stakeholders to advance four priority objectives in the *Action Plan*.
- SEPT - MAR 2015-16** ..... ○ **MOBILIZING ACTION TEAMS:** 48 stakeholders (including caregivers) involved in four actions teams to share expertise and develop specific work plans to advance priorities.
  1. Access - Create a case for technology enabled carers
  2. Awareness – Targeted federal advocacy plan
  3. Financial – Explore respite options for carers
  4. Workplace – Engage employers in conversations about work and care
- JAN 2016** ..... ○ **AWARENESS AND OUTREACH:** Broad dissemination of *Action Plan* and group successes.
- 2016** ..... ○ **MAKING CHANGE HAPPEN**  
Sustaining the integrated and collaboration actions and achievement of shared outcomes.

## APPENDIX B. Mobilizing Action Teams

### MOBILIZING ACTION TEAM: CREATING REAL CHANGE FOR CAREGIVERS

Through a collaborative and a shared model of engagement, Mobilizing Action Teams (MAT) plan, lead and undertake the execution of tactics to advance key objectives—awareness, access, financial, and supportive workplaces.

Carers Canada facilitates collaboration and operational coordination through the maintenance of the Mobilizing Action secretariat. This include ensuring collaborative engagement of Mobilizing Action Teams, facilitating ongoing active involvement of carers and supporting strategic communications.

AWARENESS MOBILIZING ACTION TEAM			
PARTNERS	MOBILIZING ACTION (NOV 2015- MAR 2016)	MAKING CHANGE HAPPEN (PHASE 2)	SHARED OUTCOMES
<ul style="list-style-type: none"> <li>- Carers Canada</li> <li>- Canadian Home Care Association</li> <li>- Canadian Hospice Palliative Care Association</li> <li>- Canadian Nurses Association</li> <li>- Health Charities Coalition of Canada</li> <li>- Helene Hardy, caregiver</li> <li>- Janssen Inc.</li> <li>- Lorna Scott, caregiver</li> <li>- MS Society of Canada</li> <li>- Parkinson Society Canada</li> <li>- SEIU Healthcare</li> </ul>	<ul style="list-style-type: none"> <li>• Recognition in 2015 federal election</li> <li>• Prime Minister Proclamation</li> <li>• Campaign for National Carers Day – April 5, 2016                             <ul style="list-style-type: none"> <li>- MP breakfast on Parliament Hill</li> <li>- Recognizing Working Carers</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>• Political champions for carers</li> <li>• Recognize carers in national health care strategies</li> <li>• Targeted briefs on caregiving issues</li> </ul>	Recognition of carers and identification of their unique needs in government policies and programs.
ACCESS MOBILIZING ACTION TEAM			
PARTNERS	MOBILIZING ACTION (NOV 2015- MAR 2016)	MAKING CHANGE HAPPEN (PHASE 2)	SHARED OUTCOMES
<ul style="list-style-type: none"> <li>- 3M</li> <li>- Canadian Cancer Action Network</li> <li>- CBI Health Group</li> <li>- Canadian Home Care Association</li> <li>- CareLink Advantage</li> <li>- GE Healthcare</li> <li>- Memorial University of Newfoundland – Centre for Nursing Studies</li> <li>- Philips Lifeline Canada</li> <li>- Vickie Cammack</li> </ul>	<ul style="list-style-type: none"> <li>• A case for technology enabled carer</li> <li>• Funding proposal for a caregiver survey on receptivity to technology</li> </ul>	<ul style="list-style-type: none"> <li>• A caregiver survey on receptivity and the use of technology</li> <li>• Facilitate a round table on Technology-Enabled Carers</li> <li>• Vision and road map for technology-enabled carers (including priorities and actions)</li> <li>• Strategic approaches with provincial governments</li> </ul>	Improve access to caregiver support services and patient care resources
FINANCIAL MOBILIZING ACTION TEAM			
PARTNERS	MOBILIZING ACTION (NOV 2015- MAR 2016)	MAKING CHANGE HAPPEN (PHASE 2)	SHARED OUTCOMES
<ul style="list-style-type: none"> <li>- Alberta Caregiver Association</li> <li>- Alberta Health Services</li> <li>- Canadian Home Care Association</li> <li>- CBI Health Group</li> <li>- Care at Home</li> <li>- Closing the Gap</li> <li>- Nursing and Homemakers Inc.</li> <li>- Ontario Caregiver Coalition</li> <li>- PEI Health</li> <li>- SEIU Healthcare</li> </ul>	<ul style="list-style-type: none"> <li>• Scope and outline of briefing paper on respite services</li> </ul>	<ul style="list-style-type: none"> <li>• Briefing paper on respite services</li> <li>• Raise awareness of respite as a Provincial government priority</li> <li>• Engage P/T governments in dialogue on respite</li> </ul>	Flexible financial options and access to the appropriate resources that alleviate the financial burden associated with providing care
WORKPLACE MOBILIZING ACTION TEAM			
PARTNERS	MOBILIZING ACTION (NOV 2015- MAR 2016)	MAKING CHANGE HAPPEN (PHASE 2)	SHARED OUTCOMES
<ul style="list-style-type: none"> <li>- Carers Canada</li> <li>- Canadian Human Rights Commission</li> <li>- CBI Health Group</li> <li>- Mental Health Commission of Canada</li> <li>- McMaster/CIHR</li> <li>- Saint Elizabeth</li> <li>- Vanier Institute</li> <li>- Vickie Cammack</li> <li>- University of Guelph – Dr. Donna Lero</li> </ul>	<ul style="list-style-type: none"> <li>• Explore opportunities for awareness – engagement campaign</li> <li>• Support development of workplace standard</li> </ul>	<ul style="list-style-type: none"> <li>• Engagement campaign</li> <li>• Corporate champions</li> <li>• 'Carer friendly' workplace strategies and actions</li> </ul>	Create supportive workplaces that recognize caregiving obligations

## APPENDIX C. Awareness Mobilizing Action Team – Carers Brief

### SUPPORTING THE VITAL ROLE OF CARERS

Carers (i.e. family caregivers) are individuals (family members, neighbours, friends and other significant people) who take on a caring role to support someone with a diminishing physical ability, a debilitating cognitive condition or a chronic life-limiting illness.

#### THE ISSUE

Our population is aging, our citizens are living longer with more complex conditions, the need for long-term care is increasing and our health budgets are financially unsustainable.

Carers contribute an estimated \$25 billion dollars of unpaid care to our health system annually. Carers are the invisible backbone of our health care system and often sacrifice their own physical, financial, and psychosocial well-being in order to provide care to loved ones. If carers are not provided with adequate supports (physical, financial and mental), our health care system and economy will suffer serious detrimental consequences.

#### CURRENT STATUS – WHAT ARE THE FACTS?

##### **Our health system is dependent upon the unpaid contribution of carers**

- The number of carers has almost tripled in the last 15 years - from 2.85 million to over 8 million in 2012.
- On average carers provide over 80 % of the care needed by individuals with chronic conditions.
- Carers provide between 16 to 28 hours of unpaid care per month for an average of three years.
- It is estimated that family caregivers provide \$25–26 billion dollars of unpaid care every year.

##### **Carers experience negative health and financial consequences as a result of caring**

- Carers are substantially more likely to experience an array of negative emotional, social, and health outcomes, than non-carers.
- 28% of carers find providing care to be stressful, and 19% indicated that their physical and emotional health suffered as a result of caregiving.
- Collectively, carers aged 45 and older spent approximately \$1 million per month on care-related-out-of-pocket expenditures in 2006, or almost 12.6 million/year.
- The time and physical demands of balancing unpaid caregiving and work responsibilities are often equivalent to working two full-time jobs.

##### **Our economy depends on the contribution of carers**

- 6.1 million employed Canadians or 35% of the Canadian workforce are carers.
- The majority of carers (2/3) are in their prime earning years – between 45 and 64 year of age.
- 1 in 4 carers must balance childcare as well as caring for their parents.
- Being a carer impacts employment opportunities and employer productivity:
  - 1.6 million carers took work leave;
  - 600,000 reduced their work hours;
  - 160,000 turned down paid employment;
  - 390,000 had to quit their jobs to provide care.
- Employers experience high employee turnover rates and increased costs associated with hiring, training, and orienting staff when carers must leave the workforce.
- The cost to employers in lost productivity is \$1.28 billion per year.

## **Federal Leadership – Pan-Canadian Actions**

The essential role of carers to our health system and economy has been recognized by the federal government through tax measures and targeted programs (See Table I). While this is a start, more must be done to ensure the physical and financial health and well-being of carers.

While there is great diversity among carers (ethnicity, age, income, geography) there are common needs that have been identified by all carers. These needs will only be addressed through a national initiative led by the federal government.

Specifically, we propose the following recommendations for the Federal Government:

1. Raise awareness of the role and value of carers through a national awareness campaign beginning with a Prime Ministerial proclamation on the value of carers. This campaign should commence on National Caregiver Day—the first Tuesday in April.
2. Develop a catalyst fund to support innovative community-based services that provide the necessary services to protect the health and well-being of carers.
3. Enhance job security, income support, and tax deduction measures to minimize the financial burden that carers experience.
4. Fund an Employer for Carers initiative that will assist Canadian employers with supportive workplace strategies that recognize and respect employed carers' needs.

## **How our recommendations will benefit Canada**

Actions on our recommendations will alleviate the burden on carers and help new carers prepare for their necessary role as our population ages and care demands increase.

- **To Canadians:** 8.1 million carers will be able to continue to provide their dedication and compassion day in and day out, to ensure that the person they care for has the best quality of life and care possible.
- **To Employers:** 6.1 million employed carers will be supported to balance work responsibilities, personal commitments and their unpaid caring duties without detrimental effects to their employment and employers.
- **To the Health Care System:** The annual contribution of \$25 billion of unpaid care (11% of our public health care spending) will continue to sustain our health care system.
- **To the Canadian Economy:** \$1.3 billion in savings from a loss of productivity that would otherwise be incurred when caregivers are unable to balance work and care.

Table I. Current federal programs that support carers and care recipients

Program	Description
<u>Family Caregiver Tax Credit</u>	The family caregiver tax credit allows family caregivers taking care of an ill family member to claim an enhanced caregiver amount for a dependant under one of the existing dependency-related tax credits.
<u>Infirm Dependent Tax Credit</u>	The infirm dependent tax credit provides tax relief to individuals providing support to an infirm relative residing in a separate residence.
<u>Eligible Dependent Tax Credit</u>	The eligible dependant tax credit can be claimed by those who supported a dependant in their home at any time in the year.
<u>Disability Tax Credit</u>	The disability tax credit is a non-refundable tax credit which can be claimed by persons with disabilities who have prolonged impairments of their physical or mental functions.
<u>Child Disability Benefit</u>	The child disability benefit is a tax free benefit for families who care for children under age 18 with a severe and prolonged impairment in mental or physical functions.
<u>Medical Expenses Tax Credit</u>	The medical expense tax credit provides tax relief for individuals who have sustained significant medical expenses for themselves or certain of their dependants.
<u>Child Care Expense Deduction Amount</u>	The child care expense deduction amount provides some relief for taxpayers who incur child care expenses in order to work, carry on a business or undertake certain educational activities
<u>Special Benefits for Parents of Critically Ill Children</u>	Beginning June of 2013, eligible parents who take leave from work to provide care or support to their critically ill or injured child can receive these special Employment Insurance benefits for up to 35 weeks.
<u>Employment Insurance Compassionate Care Benefit</u>	These Employment Insurance benefits are paid to individuals who are away from work temporarily to provide care or support to a family member who is gravely ill and who has a significant risk of death within 26 weeks (six months). A maximum of six weeks of compassionate care benefits may be paid to eligible people.
<u>Announcements in the 2015 Federal Budget</u>	<p>Taking Action for Veterans - Creating a new tax-free Family Caregiver Relief Benefit to recognize the vital contributions of informal <b>caregivers</b> to the health and well-being of veterans.</p> <p>Tax Relief and Enhanced Benefits for Canadian Families and Individuals - Enhanced support to caregivers of infirm dependent family members by introducing the <b>Family Caregiver Tax Credit</b>, and by removing the \$10,000 limit on eligible expenses that caregivers can claim under the Medical Expense Tax Credit in respect of a dependent relative.</p> <p>Extending Compassionate Care Benefits - Economic Action Plan 2015 proposes to provide up to \$37 million annually to extend <b>Employment Insurance Compassionate Care Benefits</b> from six weeks to six months.</p>

## APPENDIX D. Awareness Mobilizing Action Team – Carers Champions Recommendation

(Name, Party, Riding)

Harold Albrect, *Conservative, Kitchener-Conestoga, ON*  
Rona Ambrose, *Conservative, Edmonton -Bruce Grove, AB*  
Raynell Andreychuk, *Conservative, SK*  
Nikki Ashton, *NDP, Churchill—Keewatinook Aski, MB*  
John Barlow, *Conservative, Macleod, AB*  
Frank Baylis, *Liberal, Pierrefonds-Dollard, QC*  
Vance Bedway, *Liberal, Niagara Center, ON*  
Carolyn Bennett, *Liberal, St.Paul's, ON*  
Candice Bergen, *Conservative, Portage—Lisgar*  
Lynn Beyak, *Conservative, ON*  
Scott Brison, *Liberal, Kings-Hants, NS*  
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Colin Carrie, *Conservative, Oshawa, ON*  
Rodger Cuzner, *Liberal, Cape Breton-Canso, NS*  
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Jean-Yves Duclos, *Liberal, QC*  
Terry Duguid, *Liberal, Winnipeg South, MB*  
Kirsty Duncan, *Liberal, Etobicoke North, ON*  
Linda Duncan, *NDP, Edmonton Stratchcona, AB*  
Doug Eyolfson, *Liberal, Charleswood-St.James-Assiniboia-Headingley, MB*  
Ted Falk, *Conservative, Provencher, MB*  
Greg Fergus, *Liberal, Hull-Alymer, Quebec*  
Hedy Fry, *Liberal, Vancouver Centre, BC*  
Ralph Goodale, *Liberal, Wascana*  
Cheryl Hardcastle, *NDP, Windsor-Tecumseh, ON*  
Mark Holland, *Liberal, Ajax, ON*  
Yvonne Jones, *Liberal, Labrador, NL*  
Bernadette Jordan, *Liberal, South Shore - St. Margaret's, NS*  
Jason Kenney, *Conservative, Calgary - Southeast, AB*  
Kamal Khera, *Liberal, Brampton West*  
Robert Kitchen, *Conservative, Souris-Moose Mountain, SK*  
Kellie Leitch, *Conservative, Simcoe—Grey, ON*  
Alistair MacGregor, *NDP, Cowichan—Malahat—Langford, BC*  
Irene Mathyseen, *NDP, London-Fanshawe, ON*  
Phil McColeman, *Conservative, Brant*  
Cathy McLeod, *Conservative, Kamloops-Thompson-Cariboo, BC*  
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Christine Moore, *NDP, Abitibi-Temiscamingue, QC*  
Robert Morrissey, *Liberal, Egmont, PE*  
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Joyce Murray, *Liberal, Vancouver Quadra, BC*  
Eva Nassif, *Liberal, Vimy, QC*  
Jane Philpott, *Liberal, Whitchurch-Stouffville, ON*  
Seamus O'Regan, *Liberal, St.John's South-Mount Peral, NL*  
Robert Oliphant, *Liberal, Don valley West, ON*  
John Oliver, *Liberal, Oakville, ON*  
Kyle Petersen, *Liberal, Newmarket Aurora, ON*  
Lisa Raitt, *Conservative, Halton, ON*  
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Sonia Sidhu, *Liberal, Brampton South, ON*  
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Karen Vechhio, *Conservative, Elgin-Middlesex-London, ON*  
Alice Wong, *Conservative, Richmond Centre, BC*  
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## APPENDIX E. Access Mobilizing Action Team: Business Case for Technology Enabled Carers

### FRAMEWORK – BUILDING THE CASE FOR TECHNOLOGY ENABLED CARER

#### WHO ARE CARERS?

Carers are family members, neighbours and friends who take on an unpaid caring role to support someone with a diminishing physical ability, a debilitating cognitive condition or a chronic life-limiting illness. Carers are also known as caregivers or family caregivers.

[Carers Canada, 2015]

#### WHO ARE TECHNOLOGY ENABLED CARERS?

Carers who are empowered and connected through the innovative use of technology. There is no age distinction, they are young and old. They are the carers of the future.

#### HOW DOES TECHNOLOGY ENABLED CARERS?

There is growing recognition that technology-enabled home care emphasizes prevention and promotes independence and enhanced quality of life. Carers who are empowered and connected through the innovative use of technology are better positioned to access relevant information, as well as live supports leading to improved:

- **Knowledge Building:** Provide access to up-to-date and relevant information in real time, so carers can make informed decisions.
- **Care Coordination:** Stay connected and help navigate through complex health care system.
- **Clinical Care:** Make clinical care simple and easy. Electronic Health Records are complete, accurate and available to all members of the care team.
- **Planning (i.e. Advance Care Planning):** Help share wishes, needs and expectations of life and death.
- **Self-Management:** Take control of one's own health and wellness.
- **Social Networking/Care Companion:** Put carers in touch with each other in a convenient easy way (i.e. peer to peer support).



**APPENDIX F. Access Mobilizing Action Team: Making Change Happen – Action Plan (Project Goals, Activities and Indicators of Project Success)**

**AREA OF FOCUS:**

Technology- Enabled Carers in Canada

**OBJECTIVE:**

Understand caregivers’ receptivity to technology (including the types of technologies and the factors/barriers that influence the use of technology) in order to define perceived value, benefit and likelihood of adopting technologies.

<b>GOAL 1A</b>		
<b>GOAL DESCRIPTION</b>	<b>ACTIVITIES</b>	<b>INDICATORS OF SUCCESS</b>
<p>Build a case to support technology enabled carers in Canada. Within the case for support:</p> <ul style="list-style-type: none"> <li>• Examine carers’ receptivity to technology</li> <li>• Assess types of technologies that are attractive to technology-using carers</li> <li>• Identify barriers to the use of technology</li> <li>• Examine enablers/factors influencing the use of technology</li> </ul>	<p>Conduct a quantitative online survey of technology-using carers (n= 100-200)</p> <p>Questionnaires:</p> <ul style="list-style-type: none"> <li>• Demographic and caregiving background</li> <li>• Caregivers’ predisposition to technology</li> <li>• Receptivity to caregiving technologies - likelihood to adopt new technologies</li> <li>• Perceived or observed benefits in the use of technologies to support their caring role</li> </ul>	<p>Technology enabled carers in Canada experience:</p> <ul style="list-style-type: none"> <li>• Improved capacity building by accessing relevant information in a timely, efficient manner,</li> <li>• Improved care coordination leading to easier healthcare navigation</li> <li>• Enhanced clinical care outcomes, including access to accurate electronic health records that are available to all members of the care team</li> <li>• Improved self-management of health and wellness</li> <li>• Awareness and support through the definition and promotion of Advance Care Planning</li> </ul>
<b>GOAL 1B.</b>		
<p>Construct a vision and road map for technology-enabled carers that includes a vision, priorities and proposed actions that address key considerations on awareness, assessment, scalability and sustainability</p>	<p>Host a national roundtable to develop an integrated vision (or coordinated “road map”) to accelerate the adoption of technology for carers in Canada.</p>	<p>An integrated road map to accelerate the adoption of technology will result in the emergence of a shared vision of technology-enabled carers for use of technology in Canada</p> <p>Improved access to support services and patient care resources for Canadian carers.</p> <p>Engagement of civil society organizations serve to advance shared priorities to focus on supporting technology-enabled carers, leading to the strategic engagement of provincial governments.</p>

# APPENDIX G. Financial Mobilizing Action Team – Scope of Briefing Paper on Respite as an Outcome

## OBJECTIVE

Provincial/territorial governments will explore a variety of funding options to provide respite for carers, starting in 2016.

## OUTCOME

A comprehensive national briefing paper articulating the business case and innovative respite models to inform and influence provincial and territorial governments’ role in supporting Canadian carers.

## TARGET AUDIENCES

- Provincial/Territorial Governments – P/T engagement to increase awareness of needs for respite and consideration of respite options
- Diverse stakeholders (carers, care and service providers, health planners and policy makers) - Collaborate and collectively advocate for increased public funding and targeted respite for carers.

## RATIONALES:

- Carers face caregiving demands and expectations that can result in significant physical, financial, social and emotional impacts. They must manage many situations including lengthy hospital stays, frequent medical appointments, and complicated care regimes in the home.
- Introduce greater consistency in care, a better understanding of the services available, more support for carers and, ultimately, better access to the right care for those who need it most (the vulnerable population)
- Ensure the sustainability of our health care system - carers fill the gap of the health human resources shortage

## SCOPE OF THE BRIEFING PAPER:

### • What is Respite Care?

#### DEFINITION

(i.e. Respite services are defined as any service that temporarily relieves a family caregiver from the responsibilities of providing care and improves or sustains the caregiver’s well-being. Respite services can be provided in the clients home, in the community or in a facility.

Or

Respite for caregivers involves a break from caregiving responsibilities. Respite can take any number of forms, as long as they meet the caregiver’s self-defined needs for relief, time off, a break from caregiver responsibilities and/or the experience of some rejuvenation and peace of mind.)

### • Type of supports & Outcomes

#### SERVICES

Ex.

- In-home services
- Community access respite
- Centre-based day program
- Residential respite care (short-stays in LTC)
- Palliative Care

#### OUTCOME

Ex.

- Improvement in caregiver’s well-being
- Feeling recognized and valued as a caregiver
- Time off without worry or guilt
- Sharing the caregiving load with the family
- Emotional and social support
- Empowerment through information and access to knowledge and tools

- **Why is it critical?**  
The challenges faced by carers and the ripple effect on our health care system, economy and society as a whole
- **What is working?**  
Promising Practices – Canada & International  
Benefits across the Canadian care system/spectrum (i.e. patients & caregivers, providers, Health Care System)
- **What's next?**  
Recommendations/considerations for provincial and territorial governments to better support carers in achieving 'respite'

## APPENDIX H. Supportive Workplace Mobilizing Action Team – Online Consultation Result

### COMMUNICATION AND ENGAGEMENT RECOMMENDATIONS

#### OBJECTIVE:

To capture the attention of employers in Canada, to engage their whole selves, to reframe the conversation, and to make real change happen for employees with caregiving responsibilities, commitment and obligations

#### WHO ARE CARERS?

Carers are family members, neighbours and friends who take on an unpaid caring role to support someone with a diminishing physical ability, a debilitating cognitive condition or a chronic life-limiting illness. Carers are also known as caregivers or family caregivers.

[Carers Canada, 2015]

#### WHO ARE EMPLOYEE CARERS?

The 6.1 million Canadians (or 35% of the labour force) who take on an unpaid caring role to support someone in their lives, while also balancing paid employment.

#### KEY MESSAGES:

Employers (i.e. HR professionals, practitioners, general managers, owner/operators etc.) need statistics to build a case for action however, as important or in most cases what is even more important, is a need of a compelling story to capture the attention of their colleagues in high pressure, high intensity, and high performing work environments. Therefore, scenarios, case studies, examples, and stories of success will be important as well.

#### Stories of Work & Care:

Carers Canada developed a visual narrative portraying the reality of millions of carers who must balance their personal commitments, unpaid caregiving and work responsibilities. The pictures and stories are a reflection of the challenges, supports that made a difference and what inspired employee carers to keep on giving. The senior leaders of home care organizations profiled in this initiative shared their commitment to employee carers and their corporate social responsibility. <http://www.carerscanada.ca/carer-voices/>

#### Facts:

The need to balance work and care has a huge impact on Canada's middle class.

- One quarter of employed caregivers spend up to 30 hours per week providing unpaid care. [Stats Canada, 2012]
- 50% of employed caregivers are between the ages of 45-65 years, experiences employees in their peak earning years. [Stats Canada, 2012]
- Consequences of caregiving on work can include emotional, psychological and physical impacts such as anxiety, worries, fatigue, anger, irritability, rise in depression and loss of sleep.
  - Impact on their attendance/availability to work
  - Impact on their attention/ability to focus or perform
  - Impact on their career development

Supportive workplace environments for working carers are good financial investments.

*(Tip: Frame as an opportunity to build profile as a leading organization, rather than a problem to solve or a crisis to avert or a challenge to overcome - appealing to the aspirational side of employers)*

- When a caregiver has access to support in the workplace (flexibility, autonomy, leaves, recognition, respects), they will remain as a contributing member of team by being able to:
  - Fulfill their responsibilities
  - Achieve their goals and meet their objectives
  - Invest in their professional development
  - Stay available and accessible
  - Mitigate the inherent stresses associated with caring and working
- When carers are supported, there are also intangible benefits observed by employers:
  - Loyalty and commitment
  - Sense of pride for being part of the organization
  - Dedication to producing quality of work
- In engaging in the caregiving and work conversation in a positive and proactive manner, employers can collectively save \$1.3 billion in productivity that results when Canadian employers successfully balance work and care. [Conference Board of Canada, 2012]

## RESOURCES AND STRATEGIES

It is important to balance the facts with the “HOW” – practical ideals, tools and resources - in creating supportive workplaces. Below are few examples that employers can consider:

- Offering flexible work arrangements
- Supportive behaviours showing that organization values the employee
- Plan for situations when employee has to leave suddenly, or unexpectedly cannot come to work.
- Providing the employee a private space to make calls and care arrangements.
- Managing co-worker concerns and reactions
- Ensuring that the workplace culture supports overall employee well-being.
- Apprising the employee of the resources that may be available through the organization’s EAP, benefits or healthy workplace plans or programs.
- Linking carer initiatives to the organization’s planning cycles
- If appropriate, providing the employee with contact and other information about resources within the community.
- Establishing policy on language and regular check-ins with the employee to see how they are doing.

Resources:

- When Work and Caregiving Collide: How Employers Can Support Their Employees Who Are Caregivers
- A Guide to Balancing Work and Caregiving Obligations
- National Standard for Psychological Health and Safety in the Workplace
- Caregiver Policy Lens

## OUTREACH

Maximize opportunities to reach our target audience, deliver our key messages and initiate engagement

- Public consultations (round table) with HR groups and employers to better understand their needs in providing supportive workplace environment, as well as accumulate ideas on promising practices
- Capacity building through management training and university courses aims to help managers recognize the sign/symptoms of burnout, factors that contribute to a healthy workplace, and conversation cues.
- Align messages with HR associations or certification program, best employers program
- Engage policy makers and politicians to influence change in legislation
- Podcasts and education seminars to key stakeholders to engage and educate on programs and best practices available.
- Social Media/ Print News to generate awareness