



Canada, a Caring Society:

Action Table on Family Caregivers

Informed dialogue, leading to concrete action for all Canadians



ACKNOWLEDGEMENTS

Canada, a Caring Society: Action Table on Family Caregivers is an initiative of the Canadian Cancer Action Network working in partnership with the Canadian Cancer Society, Canadian Caregiver Coalition and the Mental Health Commission of Canada. The initiative was funded by the Canadian Partnership Against Cancer.

This report was prepared by Leslie Greenberg Consulting working in close collaboration with the **Canada, a Caring Society: Action Table on Family Caregivers** Project Planning Committee and the National Caregiver Advisory Committee.

This initiative was led by Marjorie Morrison, Chief Executive Officer of the Canadian Cancer Action Network. The report was designed by Marjorie Morrison and Fay Bennie, Canadian Cancer Action Network.

In consultation with Leslie Greenberg Consulting, the Project Planning Committee included:

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

Nadine Henningsen, Canadian Caregiver Coalition

Pam King, CCAN Manitoba

Tommi Laulajainen, Canadian Partnership Against Cancer

Marjorie Morrison, Canadian Cancer Action Network

Denise Page, Canadian Cancer Society

Adam Waiser, Canadian Cancer Society

Liz Wigfull, Mental Health Commission of Canada

The National Caregiver Advisory Committee included:

Odette Beaudoin

Wendy Bell

Helene Hardy

Kellie Huffman

Lori Synes Taraba

The Canadian Cancer Action Network wishes to acknowledge the efforts of John Douglas and Erin Crawford of the Canadian Cancer Society—Manitoba Division, as well as Linda Venus and the CCAN Manitoba team for input in the area of financial hardship. Further, we wish to thank those who generously volunteered their time to facilitate and document the breakout sessions.

The Project Planning Committee wishes to gratefully thank Dr. Ella Amir for her keynote address, and Jacquelin Holzman for her opening comments.

For more information about this initiative, or to discuss this report, call **416.619.5784** or visit **www.ccanceraction.ca**.

TABLE OF CONTENTS

Message from the CCAN CEO and Chair	1
Summary	2
Who Cares for the Caregivers?	3
Introduction	4
Context for Action	5-6
Strategic Priorities	7
Enhance awareness of caregiver financial burden	8-11
Improve access to resources/support services	11-14
Create more flexible workplace environments	15-17
Adapt/adopt government support programs	18-22
Moving Forward	22-24
Appendices	
Appendix A: Agenda	25
Appendix B: Participant List	26-28
Appendix C: Sample Initiatives	29-34
Appendix D: Meeting Evaluation	35
Appendix E: About the Partners	36
Endnotes	

Canada, a Caring Society: Action Table on Family Caregivers

MESSAGE FROM THE CCAN CEO AND CHAIR

On behalf of the Canadian Cancer Action Network and our project partners, we are pleased to provide a summary report of ***Canada, a Caring Society: Action Table on Family Caregivers***.

We have been greatly encouraged by the stakeholder response to this event, and inspired to witness the passion of the many groups and individuals working to foster better support for Canada’s eight million family caregivers.

As illustrated in this report, too many parents, spouses, children, siblings or friends face often devastating financial hardships as a result of their caregiving. The reality for many families affected by life-limiting or life-threatening illnesses means having to sell their home, declare bankruptcy, or live on welfare. Family caregivers deserve, and are entitled to, better support.

To this end, we joined forces with the Canadian Cancer Society, Canadian Caregiver Coalition and the Mental Health Commission of Canada to build on each other’s efforts and to further identify opportunities for broader pan-Canadian collaboration. In so doing, we firmly believe we are

in a position to help caregivers provide better care for their loved ones, safeguard their own wellbeing, and generate savings in our health-care system.

In planning the strategic focus for the caregivers forum, we recognized that we could not address every issue related to financial hardship. With a commitment to move from dialogue to action, we chose to focus on those areas of shared priority and where we might best be positioned to act initially.

The Canadian Cancer Action Network, as an umbrella organization representing the interests of more than 85 member organizations across Canada, is ideally positioned to act as a catalyst for change by bringing cohesion to pan-Canadian efforts to address caregiver financial hardships. While the forum was a step toward broader collaboration, the need to develop a National Task Force on Family Caregivers in Canada to continue dialogue and accelerate action is essential.

In closing, we wish to express our gratitude to the caregivers who so generously gave of their time and informed all aspects of this meeting. We also extend our sincere appreciation to the Canadian Partnership Against Cancer, whose financial support enabled this event and the opportunity to exchange ideas and evidence.



Marjorie Morrison, CEO



Jacquelin Holzman, Chair

SUMMARY

Canada's family caregivers contribute more than \$5 billion annually through their unpaid labour.¹ In fact, half of this country's homecare costs are borne by caregivers of family or friends with life-limiting or life-threatening illness.²

Despite the scale of their unpaid contribution, many family caregivers suffer financial hardship and are in need of support to cope with their caregiving responsibilities. In 2012, 28% of Canadians who cared for a child and 20% of those who cared for a spouse experienced financial difficulties.³ Ontario families of children with cancer, for example, incur an average of more than \$28,000 in costs in the first three months following a child's diagnosis.⁴

In an effort to mobilize broader action in addressing this issue, four of the nation's leading cancer, mental health, and caregiver groups jointly hosted ***Canada, a Caring Society: Action Table on Family Caregivers***. Funded by the Canadian Partnership Against Cancer, the day-long forum 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.

The event brought together more than 40 stakeholders and caregivers from across Canada to develop concrete solutions to reduce the financial hardships facing so many of Canada's family caregivers. Foundational reports released by the event partners formed the basis of the discussion, with emphasis on moving from research and recommendations to action on four cross-cutting themes:

Awareness. Underscoring the contribution of Canada's family caregivers and the need for increased support to offset the financial strains of their work.

Access. Improving access to resources and support services.

Workplace. Creating more flexible workplaces that support caregiving obligations.

Policy. Adapting government support programs towards a more caregiver-friendly model.

Forum participants highlighted a number of ways to advance action and enable greater progress for caregivers. The Canadian Cancer Action Network (CCAN), acting as a catalyst is ideally positioned to bring cohesion to pan-Canadian efforts that address caregiver financial hardships. The forum was a step towards broader collaboration.

Moving forward in 2014, CCAN will continue to mobilize collaborative action by convening a National Task Force on Family Caregivers in Canada to promote national dialogue and oversee the development of an action plan.

WHO CARES FOR THE CAREGIVERS?

Dr. Ella Amir, Keynote Speaker



For years, caregiving has been viewed as the duty of caregivers only. Society has been slow to catch up and recognize that caregiving should be a preoccupation undertaken not only by caregivers, but shared by everyone concerned with the health, social, and economic consequences of caregiving. On a societal level it should include system planners, decision-makers and service providers; on an individual level it should concern all of us, because it appears that when, rather than if one is likely to become a caregiver, is gradually becoming the *modus vivendi* in our society.

Today's meeting is guided by the recognition that caregiving is indeed a major issue that deserves proper attention. While several attempts have been made in recent years to bring caregiving to the forefront of our collective attention, there is a long way to go. This meeting, we hope, is a proactive attempt to take some important studies and reports from the drawing board into the real life arena.

Before I try to support my observations with some statistics, let me acknowledge that there are different kinds of caregiving and unique characteristics are associated with each.

Caregiving to an Alzheimer's patient is different from caring to a child with developmental challenges or cancer, and may be quite different from caring to an adult child with schizophrenia. However the commonalities are many and this is what brings us together in an effort to voice our concerns and mobilize change.

An important common denominator that characterizes all caregivers is the burden associated with caregiving, especially when it lasts a long time. Time and again it has been demonstrated that caregiving often compromises the physical, mental and emotional health and well-being of the caregiver themselves, especially when they do not receive the support they need to exercise their responsibilities.

If we wish to maximize the benefits of caregiving for both caregivers and care recipients, mitigate the potential negative consequences of caregiving to caregivers and continue to reap the social and economic benefits of unpaid caregiving, we need to pay attention to the total burden experience of caregivers.

This meeting, however, will focus on the financial burden of caregiving. If we consider it as a start only, then we can expect to move on to other burden domains in due course and ultimately help to change the climate in which caregivers operate.

INTRODUCTION

The Canadian Cancer Action Network (CCAN), a national volunteer-driven organization comprised of more than 85 patient-centred organizations from across Canada, is dedicated to ensuring a coordinated patient and caregiver perspective is firmly embedded in work across the cancer control continuum.

On October 22, 2013 CCAN led a national forum entitled ***Canada, a Caring Society: Action Table on Family Caregivers***, in partnership with the Canadian Cancer Society (CCS), Canadian Caregiver Coalition (CCC) and the Mental Health Commission of Canada (MHCC). Guided by foundational reports⁵ released by the event partners, the forum explored ways to address the financial hardships affecting family caregivers of Canadians with life-limiting and life-threatening illnesses. Funding was provided by the Canadian Partnership Against Cancer.

Recognizing that the total burden experience of caregivers goes beyond financial considerations, the focus of this effort initially reflects the financial-related commonalities that exist across different illnesses and caregiving contexts.

The need to further advance efforts in support of caregivers is clear. As illustrated in reports by the event partners, nine-in-10 households will suffer a loss of income or rise in expenses as a direct result of a cancer diagnosis. Minimizing excessive financial burden through potential policy changes and creating more flexible workplace environments are among the major priorities of family caregivers.



Guided by a National Caregiver Advisory Committee, the forum objectives were three-fold:

1. Solicit feedback on strategies that can best address the financial realities and needs of family caregivers
2. Identify activities/initiatives across Canada that are addressing gaps in awareness, access, workplaces and government policy
3. Specify collaborative actions that can mobilize change, including ways to build on current knowledge and ongoing work.

Forty-one (41) participants attended representing caregivers, patient (consumer) groups, caregiver organizations, service providers, palliative care organizations, governments, health professional associations and researchers from across Canada. The meeting agenda involved a mix of plenary and breakout sessions, with introductions by the event partners, a video presentation by caregiver Teresa Solta of Manitoba, and a keynote address from Dr. Ella Amir, Executive Director of caregiver support organization AMI-Québec, and a member of the MHCC Advisory Council.

This document summarizes the issues discussed, learnings and recommendations for action. As a next step, CCAN's goal is to develop a National Task Force on Family Caregivers in Canada to continue national dialogue, develop an action plan (with activities, timelines and responsibilities identified) and mobilize collaborative work.

CONTEXT FOR ACTION

Caregivers are an integral part of care in all care settings. Informal caregivers are “the invisible backbone of the health-care system,” contributing more than \$5 billion of unpaid labour annually⁶ and half of the overall costs of home care.⁷ Care provided by families enables individuals to remain at home longer, and supports the services provided in facilities.⁸

THE CHALLENGES OF CAREGIVING

In 2013, Statistics Canada released a study on Caregivers in Canada. According to the study, in 2012 about 8.1 million individuals, or 28% of Canadians aged 15 years and older, provided care to a family member or friend with a long-term health condition, disability or aging needs. The study highlighted the many hardships, as well as rewards, associated with caregiving. It revealed that caregivers of children and spouses were at most risk of negative psychological, financial and employment consequences, reflecting their greater intensity of care. Of note:

- ⇒ About half of caregivers providing care to children (51%) and spouses (46%) reported at least five symptoms of psychological distress, such as depression, feelings of isolation and disturbed sleep. This compares with 30% of those caring for their own parents and 8% caring for a grandparent.
- ⇒ In addition, 34% of those caring for their child and 33% of those caring for their spouse had to consult a medical professional as a result of their responsibilities, compared with 18% of those who took care of their parents. Caregivers of children or spouses were also more likely to sustain an injury while providing care.

- ⇒ In 2012, 19% of caregivers received some form of financial support. Help from family and friends was the most common at 12%, followed by government programs at 7% and federal tax credit at 5%.
- ⇒ Those caring for their child and spouse received the most financial support from governments. In 2012, 30% of caregivers of children received government financial assistance, compared with 14% of caregivers of spouses and 5% of caregivers of parents.
- ⇒ Even though they received the most support from governments, 28% of those who cared for a child and 20% of those who cared for a spouse experienced financial difficulties. This compares with 7% among those helping their parents.

RISING EXPENSES

Further research highlights the financial strains on caregivers of children in particular. A 2010 study showed that Ontario families of children with cancer, for example, incur an average of more than \$28,000⁹ in costs in the first three months following a child’s diagnosis.

Family caregivers are often faced with numerous out-of-pocket expenses. Results from a national survey of Canadian family caregivers found that about 60 per cent pay out-of-pocket expenses (primarily transportation and medication-related costs), with 30 per cent spending over \$300 per month.¹⁰ Travel for medical care can exceed even drug costs as the largest single out-of-pocket expense borne by cancer patients and their families.¹¹

The cost of fuel, accommodation, vehicle repair and lost wage can quickly add up to tens of thousands of dollars. Because costs can be higher in rural areas, rural people face inequities based solely on where they live.

DECLINING INCOME

More than three quarters of caregivers are employed and most work full time—in 2007, employed caregivers in Canada provided an estimated 893 million hours of care annually, or the equivalent of 476,281 full time employees.¹²

In a 2007 national survey, 22% of Canadians caring for a family member or close friend with a serious health problem took one or more months off work over the course of the year to provide care.¹³

The *Mental Health Strategy for Canada* notes that caregiving can hinder participation in the workforce and cause caregivers serious economic hardship. One study reported that “27% of caregivers lost income and 29% incurred major financial costs related to caring for a family member”.¹⁴

THE NEED FOR SUPPORT

Failure to recognize, acknowledge and support family caregivers heightens their risk of becoming “collateral casualties” of the illness, compromises their health, reduces the efficacy of the help they can provide to their relatives, and increases costs to the health and social service systems. Family caregivers who are well supported are likely to provide better care for relatives, generate savings in the system and enhance the benefits of caregiving.

Caregivers who are unable to tend to their own wellbeing may impact their own health, limit the effectiveness of the help they can provide to relatives and increase costs to the health and social service systems. To reduce the risks and enhance the benefits caregiving can provide to the caregiver and care recipient, adequate supports are vital.

Dr. Ella Amir, Executive Director of caregiver support organization AMI- Québec and a member of the Mental Health Commission of Canada Advisory Council.



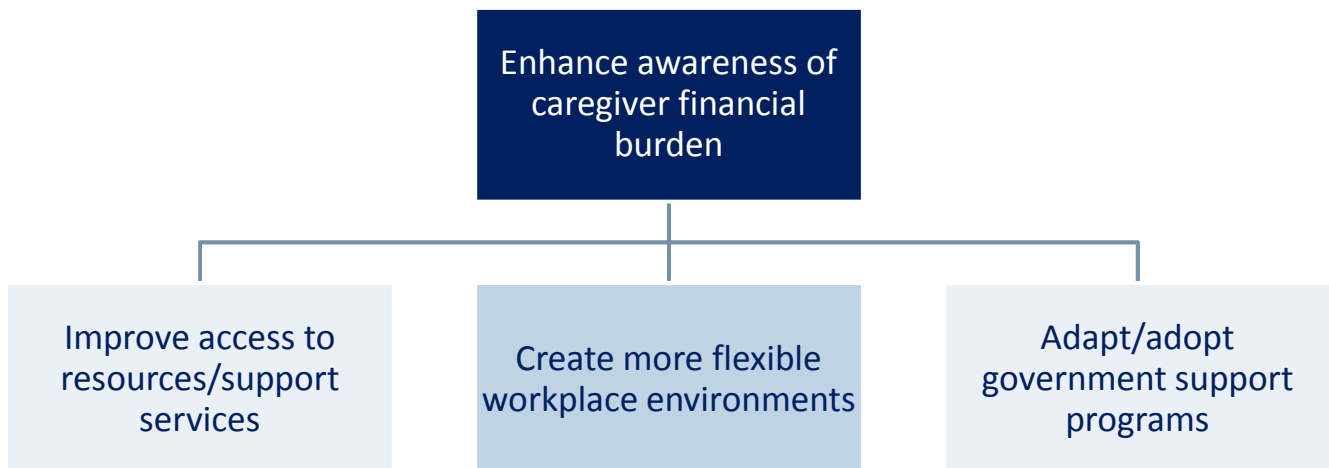
STRATEGIC PRIORITIES

STARTING POINTS FOR ACTION

Reports released by the organizers of *Canada, a Caring Society: Action Table on Family Caregivers* explore the emotional, physical, social and/or financial impacts on families living with life-limiting or life-threatening illness, as well as offering recommendations for improving a caregiver’s capacity to provide the best possible care to their loved ones while maintaining their own wellbeing.

While many of the recommendations are illness-specific, many commonalities are found across the reports. In particular, recommendations related to the financial burden on caregivers are similar across the different illnesses and caregiving contexts.

Those cross-cutting themes, which formed the basis of discussion during the forum, can be categorized in four over-arching areas representing strategic priorities as starting points for collaborative, sustainable action.



ENHANCE AWARENESS OF CAREGIVER FINANCIAL BURDEN

WHAT WE KNOW

Considering the scale of their contribution, financial support to caregivers should be seen as a cost-effective investment in managing public health-care costs. There continues to be a lack of awareness and understanding throughout the system of the contribution of family caregivers and the financial burden many face, which may impact availability of financial support, information and resources. Greater public awareness and stakeholder engagement can create a more supportive environment for meaningful changes that address this financial burden.

WHAT WE HEARD

As an action priority, the recommendation in reports by the event partners focused on enhancing public awareness and stakeholder engagement in the caregiver financial burden.

Examples of potential action include:

- ⇒ Measure current level of awareness and support
- ⇒ Document/record and promote caregiver experiences through stakeholder channels
- ⇒ Build relationships with media and experts/spokespeople
- ⇒ Consider engaging a high profile individual, with corporate support, to shine a spotlight on the issues and the need for change

Participants in this breakout discussion agreed that there is an overall lack of awareness and understanding of the contributions family caregivers make (to families, our health system, and society) and the financial burden many face. Efforts need to focus on moving Canadians to agree that caregiver financial hardship is a problem and there is a need for change. This will set the stage for the 'asks' to follow.

Participants categorized action in **six broad themes:**

1. Ensure caregivers are central to the effort
2. Engage high-profile champions shine a spotlight on the issues
3. Be clear on the ask/story, and develop simple yet targeted messaging (audience-specific)
4. Develop targeted outreach strategies
5. Collate/build the supporting documentation that best illustrates the need
6. Actively engage media/social media

CURRENT STATE

Low-limited awareness, misunderstandings & stereotypes



DESIRED OUTCOME

Canadians are aware of the financial hardships facing caregivers and understand the need for change; key statistics and "not if but when"

Based on participant engagement, the following synthesis of proposed activities were recommended in order to change attitudes, values and behaviours, and the roles stakeholders can play in facilitating success.

Participants were asked to consider where they might intersect with the activities identified; it should be noted that some indicated a broad alignment (e.g., can assist with “awareness”), and in those cases they have been categorized below based on their organizational mandate and focus.

Activities:	Where Participants Intersect:
<p>Caregiver Engagement:</p> <ul style="list-style-type: none"> • Involve caregivers in every step of the process; not just through testimonials • Include caregivers who might not self-identify as such, those whose caregiving experience is over, and diversified contexts 	<p>Patient/consumer groups:</p> <ul style="list-style-type: none"> • The MS Society, via volunteer engagement (including caregivers) and public awareness <p>Caregiver participants:</p> <ul style="list-style-type: none"> • As childhood cancer advocates; help creating awareness/media campaigns; voice in the media; development of packages of resources for health-care professionals; assistance in developing post-event action plan and with translation
<p>High-profile champion(s):</p> <ul style="list-style-type: none"> • Engage key government figure who either has been in a caregiving role or is aware of the issues to be our voice within government 	
<p>Clear ask/story:</p> <ul style="list-style-type: none"> • Have the “30-second elevator speech” as well as targeted messaging per audience (e.g., not if but when for general public); solidify caregiver definition; remember diversity in the messaging, acute versus long-term, and the mental health dimensions of caregiving • Equip stakeholders with key messages for use within their channels (network of message delivery carriers) 	<p>Patient/consumer groups:</p> <ul style="list-style-type: none"> • Canadian Cancer Society <p>Caregiver organizations/service providers:</p> <ul style="list-style-type: none"> • Manitoba Caregiver Coalition: continue to raise awareness of caregivers and the financial burden they incur • Canadian Caregiver Coalition, through promotion of key messages to caregiver organizations and communications with key stakeholders <p>Palliative care organizations:</p> <ul style="list-style-type: none"> • Canadian Virtual Hospice via awareness raising <p>Researchers/Experts:</p> <ul style="list-style-type: none"> • Penny MacCourt, BC Psychogeriatric Association through dissemination and increased awareness of caregiver issues

<p>Targeted outreach:</p> <ul style="list-style-type: none"> • Bundle messaging and promotion by audience; for instance: <ul style="list-style-type: none"> ⇒ Target the general public, health-care delivery institutions/settings, and health professionals (via university and ongoing professional development) about challenges caregivers face and how they can be supported ⇒ Partner with professional organizations (e.g., CMA), as well as government departments (e.g., Health Canada Grants and Contributions programming) for education and awareness ⇒ Consider education in life planning courses in high schools 	<p>Patient/consumer groups:</p> <ul style="list-style-type: none"> • MHCC, by incorporating various actions into communications plan for their guidelines for caregiver support • CCAN: promote awareness nationally • Ontario Parents Advocating for Children with Cancer as a communications and awareness link to their membership <p>Health professional associations:</p> <ul style="list-style-type: none"> • Canadian Medical Association: help increase public awareness with other stakeholders <p>Governments:</p> <ul style="list-style-type: none"> • Benefit Programs Directorate; Manager, Disability Tax Measures; Manager, DTC Program can help raise awareness of Canada Revenue Agency Programs, Tax Credits • Policy analysts at Health Canada can explore opportunities with existing funding programs within Health Canada – project-based, research (e.g., scans, awareness)
<p>Supporting documentation may include:</p> <ul style="list-style-type: none"> ▪ Bank of statistics with stories attached to each ▪ List of financial hardships incurred (e.g., cost/week of feeding supplies post-hospital discharge, etc.) ▪ Scan of P/T financial support policies (process, amount, timeline); scan of non-governmental leading practices ▪ Toolkit of materials for awareness activities, including a single portal for info and support to caregivers (for service providers, see caregivertoolkit.ca) ▪ For governments (e.g., presenting at Financing Committee in Budget preparation), clear project objective, outcomes (e.g., assessment of cost savings of caregiver support on patient outcomes), \$ cost from Budget needed 	<p>Patient/consumer groups:</p> <ul style="list-style-type: none"> • Canadian Coalition for Seniors Mental Health with practical tools (tools development) for practitioners <p>Caregiver organizations/service providers:</p> <ul style="list-style-type: none"> • Canadian Caregiver Coalition via repository and caregiver support re: how to access services <p>Researchers/experts:</p> <ul style="list-style-type: none"> • Janet Fast, researcher: provide evidence to help inform/make case to stakeholders
<p>Media engagement:</p> <ul style="list-style-type: none"> ▪ National event focal point or key media event / campaign to gain attention (e.g., PSAs featuring key statistics/media program to Bell anti-stigma campaign); ask Globe and Mail to issue an article on caregiver financial burden; use social media 	<p>Patient/consumer groups</p> <ul style="list-style-type: none"> • CCAN Manitoba, via links with CancerCare Manitoba, CCAN and its nearly 90 organizations

	<p>Caregiver organizations/service providers:</p> <ul style="list-style-type: none"> Care-ring Voice Network through increased awareness, marketing and social media <p>Researchers/experts:</p> <ul style="list-style-type: none"> Dan Mornar, patient/parent advocate at BC Children’s Hospital with awareness-raising
--	--

IMPROVE ACCESS TO RESOURCES/SUPPORT SERVICES

WHAT WE KNOW

A key part of awareness-raising is ensuring caregivers understand the range of financial support options currently available to Canadians.

For example, the partnership between Human Resources and Skills Development Canada (HRSDC) and the Canada Revenue Agency has been very successful in promoting the Registered Disability Savings Program (RDSP), according to one participant from the pre-event survey. The RDSP helps Canadians with disabilities and their families save for the future.

It was noted that there are a number of organizations and social media sites that include information about government benefit plans, tax credits, housing renovation grants, and other governmental and non-governmental funding sources available across Canada. Caregivers seeking information about their financial options would benefit from greater promotion of, and increased access to, these resources.

Among those referenced, the [Family Caregiving for People at the End of Life](#) website offers information about government benefit plans, tax credits, funding sources or housing renovation grants available across Canada. Other sites with financial support information include [Canadian Virtual Hospice – Financial Benefits](#), [Caregiver-Connect \(VON Canada\)](#), [The FamilyCaregiver.com](#).

The *future* financial safety and security of a loved one can be a preoccupation, particularly for caregivers of people living with mental illness. In cases where caregiving may be a longstanding commitment, wills and estate planning can help caregivers address this concern, as well as government supports such as the RDSP referenced above.

A lack of public awareness of the caregiver financial burden also may explain the scarcity of community programs addressing this issue. Canadians generously donate to cancer research, for example, but seem unaware of the everyday financial crises of many families dealing with cancer. The private and not-for-profit sectors can play a role in expanding the sources of caregiver assistance, either through direct financial aid or in-kind support.



WHAT WE HEARD

Based on event partner reports:

- ⇒ Undertake a systematic review of all existing financial supports across Canada (government, corporate, community) to identify leading or promising practices for potential broader application.
- ⇒ Through public education aimed specifically at caregivers and health-care providers, increase awareness about existing financial support programs (both governmental and non-governmental), including eligibility criteria and appeal processes.
 - ⇒ As part of this activity, compile a list of resources and advice for caregivers
 - ⇒ Include information and tools for family caregivers on financial planning at various points of service, such as family caregiver organizations and notary offices
- ⇒ Informed by leading practices, increase ways for corporate sponsors, community organizations and individual donors to:
 - ⇒ Expand volunteer community services to help drive people to and from appointments
 - ⇒ Provide direct assistance in the form of gas, parking and restaurant vouchers
 - ⇒ Have special hotel rates for patients (e.g., similar to 'seniors days' at some hotels)
 - ⇒ Channel more donations toward family essentials

Although employer-related activity (e.g., flexible workplaces) is covered in the next section, participants in this breakout session referenced employers as a key access point for information and conduit to reach caregivers.

Much of the discussion in this breakout session

focused on the need for caregiver assessment and engaging caregivers through their health teams. There are innovative corporate and not-for-profit practices that could be further leveraged, and new ideas were presented for consideration.

Recommended activities are classified in **five over-arching categories:**

1. Scan and document existing financial and in-kind supports, resources and programs across Canada
2. Identify and assess caregivers
3. Provide supports/educate caregivers about the supports available
4. Educate health teams, employers and financial planners as a conduit to caregivers
5. Publicize and foster support for not-for-profit practices that channel efforts towards family essentials



A synthesis of the activities proposed is outlined below. As illustrated, providing supports or educating caregivers about the supports available is the area most identified for participant involvement.

There are gaps in identifying participation around caregiver assessment activity, and facilitating ways to encourage direct community support.

Activities:	Where Stakeholders Intersect:
<p>Scan and document available supports:</p> <ul style="list-style-type: none"> • Scan and share policies/benefits and advocacy approaches available, including internationally (ensure actions are built in systematic review of practices) • McConnell Family Foundation conducted an audit of caregiver resources across Canada • Also consult Senate Aging Report, Palliative Care Report, Kirby Report on Mental Health to identify caregiver recommendations 	<p>Caregiver organizations/service providers:</p> <ul style="list-style-type: none"> • Caregivers Nova Scotia; Nova Scotia Department of Health and Wellness: undertake systematic review
<p>Identify and assess caregivers:</p> <ul style="list-style-type: none"> • Ensure caregiver assessment is part of health-care process at point family member first gets ill; ask caregivers (multiple asks) whenever they interact with any system how they are doing and how we can help <ul style="list-style-type: none"> ⇒ Key is to ensure caregivers are identified and assessed (many do not identify themselves as such) ⇒ Caregiver assessment tool already developed; needs to be implemented ⇒ Work with schools of nursing and social work to include education on case management and caregiver assessment ⇒ Adopt palliative approach – consider patient, family and caregiver network – in providing care 	
<p>Provide supports/educate caregivers:</p> <ul style="list-style-type: none"> • Create an information pamphlet for caregivers listing financial help and support groups (user-friendly, easy to access, timely, both printed and online, different languages) • Create a model to support planning for caregiver (i.e., transitions) – provide info and supports for each stage 	<p>Patient/consumer groups:</p> <ul style="list-style-type: none"> • MS Society: needs assessment; background in caregiver development; help in development of navigator strategy

<ul style="list-style-type: none"> • Push information rather than caregivers having to access on their own (e.g., the Alzheimer Society First Link program connects families to services and support) • Review specific challenges of First Nations, Inuit, remote, rural with programs tailored to meet needs (diversity) 	<p>Caregiver participants:</p> <ul style="list-style-type: none"> • Encouraging a system with trained navigators to welcome patient and caregiver, and facilitate access to their needs <p>Caregiver organizations/service providers:</p> <ul style="list-style-type: none"> • Canadian Virtual Hospice: partnering to develop resources to support caregivers; provide access to info about services • Manitoba Caregiver Coalition: be a conduit of access to supports and resources
<p>Reach caregivers through health teams, employers and financial planners:</p> <ul style="list-style-type: none"> • Ensure service providers are aware of programs and services for caregivers or have a caregiver coordinator who will connect with all caregivers • Educate employers about needs of caregivers, and government policies and programs for which they are eligible • Work with financial planners to encourage planning around caregiving/anticipating illness/longer-term financial security 	<p>Researchers/experts:</p> <ul style="list-style-type: none"> • Penny MacCourt, BC Psychogeriatric Association – we have 1-stop web resource for service provider to facilitate caregiver support. You could post info about resources, programs across Canada
<p>Encourage direct community support:</p> <ul style="list-style-type: none"> • Informed by systematic review, increase ways for funders to support promising practices • Build on transportation programs, like those offered by Canadian Cancer Society • Create awareness of not-for-profit initiatives such as Give-a-Mile, which funds air transportation through micro donations of air miles • Explore new ideas for sponsorship (e.g., “CanadInns caregiver accommodation benefit”, “Canada Safeway caregiver food voucher”) • Consider other corporate partnerships to help alleviate burdens, such as re-negotiating credit card rates or insurance policy coverage 	

CREATE MORE FLEXIBLE WORKPLACE ENVIRONMENTS

WHAT WE KNOW

Caregivers in the workforce may need to reduce hours or adjust responsibilities as a result of their caregiving role. Such adjustments may result in some cost to themselves and other family members, and in other negative consequences.¹⁵

The *Mental Health Strategy for Canada* asserts that family caregivers require family-friendly workplace policies (e.g., caregiver leaves, flexible hours) to reduce the likelihood of loss of income due to caregiving responsibilities. Family caregiver-friendly policies would benefit not only family caregivers but also employers and society.

Flexible work arrangements can include the adjusting of regular work hours, job sharing, telecommuting and the provision of caregiver leaves. The ability to work from home is another form of flexibility. As well, a “donated sick leave policy” allows employees’ accrued sick leave to be donated to a leave pool for sharing with caregiver employees in certain circumstances.¹⁶

GSK provides employees a leave from work so they can provide care and support to an immediate family member in cases of critical or terminal illness or other extraordinary circumstances. The benefit provides for up to 13 weeks leave over a two-year period. Those with at least three years of service can receive the 13-week leave at full salary.

The Home Depot, TELUS Corporation, KPMG and Bayer are all on the list of Canada’s Top 100 Employers for 2011 in part for their caregiver-friendly workplace policies (see Appendix D).



WHAT WE HEARD

The event partners, in their reports, suggested the following for priority focus:

- ⇒ Increase awareness and understanding among employers of how workplace policies and job displacement can compound the complex financial pressures faced by caregivers, and how a lack of flexibility contributes to financial hardship.
- ⇒ Encourage employers to offer flexibility at work, information and assistance, and emotional and other supports.
 - ⇒ Identify and build on leading and promising practices that respect caregiving obligations (e.g., implement psychological health and safety policies, such as flexible workplace policies, and adapting/adopting the National Standard on Psychological Health and Safety in the Workplace)¹⁷
 - ⇒ In addition to offering flexibility at work, employers can support their staff involved in family caregiving by providing information on community resources, services offered through the company, wellness programs, and access to resources about caregiving.

Major themes emerging from this discussion

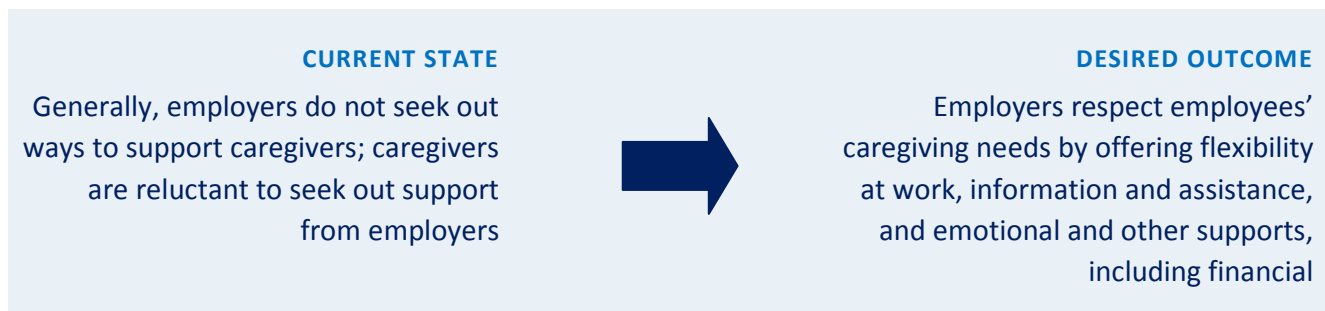
focused on the need to widen stakeholder engagement to advance workplace issues, including unions, HR associations, insurance companies and the media. There must be a compelling business case for change around workplace flexibility and leave, and caregiver experiences must be an integral part of any supporting documentation.

There is significant research underway, and thus opportunities to leverage both existing and new evidence. There are some compelling workplace practices that could be shared more broadly as a means to encourage further adoption.

Strategies must consider the self-employed, unemployed, marginally employed and young caregivers.

Participants see action categorized in **four broad themes:**

1. Collate/build the business case and related documentation supporting caregiver-friendly workplaces
2. Identify leading practices that respect caregiving obligations
3. Develop and implement outreach and education strategies, including widening stakeholder engagement to make the case
4. Encourage and help facilitate adoption/adaptation of leading practices



Activities:	Where Participants Intersect:
<p>Build the business case:</p> <ul style="list-style-type: none"> • Document caregiving’s financial impact on employees (e.g., # of bankruptcies or moves to social assistance) and employers • Compile evidence of the benefits of caregiver-friendly workplaces (to employees, employers, insurance cos.) • Develop and refine messages • Harness the power of the caregivers story to move decision-makers to action (by always having them physically present) <p>⇒ Have a caregiver with us at every point, at every meeting, at every conversation</p>	<p>Governments:</p> <ul style="list-style-type: none"> • Employment and Social Development Canada: deepening knowledge base (research; case studies); facilitating knowledge transfer; working to identify and encourage industry champions <p>Researchers/Experts:</p> <ul style="list-style-type: none"> • Janet Fast, researcher: provide evidence to make business case to employers • Other leading researchers “doing a lot of good work” (e.g., Linda Duxbury, Carleton Allison Williams [see below])

<p>Identify leading practices:</p> <ul style="list-style-type: none"> • Identify leaders and model policies, programs and approaches 	<p>Researchers/Experts:</p> <ul style="list-style-type: none"> • Allison Williams, McMaster University: research on caregiver-friendly workplace policies (5-year program of research begins April 2014)
<p>Educate employers:</p> <ul style="list-style-type: none"> • Engage unions, HR associations, insurance companies and media in strategies ⇒ Create a movement, with champions at all levels • Raise awareness with employers of the cost benefits of supporting employees balancing work and care • Showcase leading practices 	<p>Caregiver organizations/service providers:</p> <ul style="list-style-type: none"> • MS Society: Labour force strategy and engagement • MHCC: Promotion of best practices and research on caregivers in the workplace; education to employers (Webinars, spring 2014) • CCS: public awareness activity • Manitoba Caregivers Coalition: focus groups (Chambers, Human Resources and various stakeholders); help develop toolkit for businesses <p>Governments:</p> <ul style="list-style-type: none"> • Employment & Social Development Canada, Seniors Policy: policy priority, balancing work and care • Seniors and Healthy Aging Secretariat, Province of MB
<p>Help facilitate caregiver-friendly workplaces:</p> <ul style="list-style-type: none"> • Enhance employer capacity to offer information and support ⇒ Provide referral materials, toolkit, and educate managers, human resources and others ⇒ Education programs developed for employers to assist through EAP ⇒ Remember diversity lens, and fair distribution/access • Identify and promote “easy wins” (e.g., caregiving as an explicit category in policies and tracking, employer donation match, “work buddy”, etc) • Develop and provide frameworks for implementation, with action steps ⇒ Work with EAP companies – help them develop effective caregiver support programs for their (employer) clients • Government incentives for employers to create a more compassionate workplace 	<p>Patient/consumer groups:</p> <ul style="list-style-type: none"> • AMI-Quebec: promote incrementally the implementation of the recommendations in the Mental Health Guidelines throughout the system (information, access, policy, workplace) • MHCC: as part of implementing Psychological Health & Safety Standard in the Workplace <p>Caregiver participants:</p> <ul style="list-style-type: none"> • Through workplace experience, and author on EAP programs (Quebec)

ADAPT/ADOPT GOVERNMENT SUPPORT PROGRAMS

WHAT WE KNOW

Family caregivers may be eligible for various forms of assistance from the federal government, such as Employment Insurance (EI)

Compassionate Care Benefits, the **Family Caregiver Tax Credit**, the Canada Pension Plan (CPP) **Child-Rearing Provision**, and the **Registered Disability Savings Plan (RDSP)**. See Appendix D for more detail on these programs.

As described in the reports of the event partners, these federal programs have some limitations:

- With the EI Compassionate Care Benefits, only six weeks of benefits are provided, death of the family member must be imminent (i.e., within six months), and there is limited flexibility in how it can be taken (e.g., all of the benefit must be used within a six-month period and partial weeks are not allowed).
- The new Family Caregiver Tax Credit marks a good first step by recognizing the financial burden that families living with life-limiting and life-threatening illnesses face. However, more work can be done to improve accessibility to, and the immediacy of, funding. The UK and Australia, for example, pay a small cash benefit to the family caregiver of individuals requiring chronic at-home care.¹⁸
- The CPP Child-Rearing Provision is for eligible workers when they stopped work or had lower earnings while they had a child under age seven. Other family caregivers who must temporarily leave the workforce are not eligible for this benefit, thus jeopardizing their retirement earnings.



A number of provinces—Manitoba, Quebec and Nova Scotia—provide financial benefits through tax relief or government programs. See Appendix D for more detail on these provincial benefits.

WHAT WE HEARD

With some adaptation, federal government support programs for Canadians can be made more caregiver-friendly.

Expand EI compassionate care leave provisions:

- ⇒ Increase the benefit period to 26 weeks, accessible during a 52-week period
- ⇒ Build more flexibility into how the program can be used – for example, allowing partial weeks over a longer period rather than blocks of weeks at a time
- ⇒ Revise the eligibility criteria from “significant risk of death” to allow special leave for the care of persons with chronic life-limiting or life-threatening conditions
- ⇒ Allow more than one family member to use the benefit at the same time.

Extend CPP provisions:

- ⇒ Extend this provision to protect the retirement earnings of caregivers who temporarily leave the workforce to care for a person living with a life-limiting or life-threatening illness.

Make current tax credits for caregivers 'refundable' or offer an 'allowance':

- ⇒ With a refundable tax credit, the entire credit amount is either deducted from any taxes owed or entirely refunded to help offset caregiving costs.
- ⇒ Alternatively, provide more direct assistance through a modest caregiver allowance, based on revenue (which benefits those with low income or unemployed).

As well, government support programs in Manitoba, Quebec and Nova Scotia can be adapted to other jurisdictions.

Participants in this session recognized a need to move from a currently fractured caregiver policy environment to one that is more consistent across jurisdictions, reflects different caregiver obligations and contexts, provides enhanced support, and is better integrated across governments, departments and sectors.

How to achieve changes in policy was the primary focus of discussion in this breakout session. Many of the suggested actions overlap with other sessions, such as the need for caregiver-centered action, awareness-raising, and building evidence/the business case.

During this session, participants referenced the need to break down policy silos and facilitate cross-cutting collaboration (intergovernmental, F/P/T and municipal, across sectors such as non-governmental organizations and business, transportation and housing). As well, that funding is paramount to any policy success, both in terms of sparking (through knowledge mobilization and communications) and effecting change.

In addition to the policy recommendations noted in the reports of the event partners, some participants suggested the development of new policies, as outlined in the chart below. Current financial supports skew to the employed, and any adapted or new policies must consider the unemployed and precariously employed.

The **main categories for action** are as follows:

1. Ensure caregivers are central to the effort
2. Scan and document leading practices across provinces and territories, as well as internationally
3. Collate/build the business case for enhanced government support programs
4. Be clear on the ask/story, and develop simple yet targeted messaging (with "local twist")
5. Advocate/educate across governments, departments and sectors
6. Continue to explore the development of new policies



CURRENT STATE

Uneven, unknown and inadequate policies; siloed policy approaches (lack of intergovernmental and cross-sectoral collaboration)



DESIRED OUTCOME

Canadians have access to enhanced government support programs that provide caregivers with an adequate level of income, longer duration of coverage, greater flexibility of use and job security

Activities:	Where Participants Intersect:
<p>Caregiver-centered action:</p> <ul style="list-style-type: none"> • Build capacity of caregiver groups to advocate • Ensure caregivers are (physically) at the table and involved in policy planning, implementation and evaluation 	<p>Caregiver participants:</p> <ul style="list-style-type: none"> • Help change government policies to reflect the reality of the caregiver
<p>Scan leading practices:</p> <ul style="list-style-type: none"> • Scan and document policies/benefits and advocacy approaches available, including internationally 	<p>Researchers/Experts:</p> <ul style="list-style-type: none"> • Penny MacCourt, BC Psychogeriatric Association: caregivertoolkit.ca can be a repository (online) for policies related to caregiving
<p>Build the business case:</p> <ul style="list-style-type: none"> • Compile evidence to support policy changes <ul style="list-style-type: none"> ⇒ Synthesize and generate new knowledge to fill gaps ⇒ Link to larger cost containment health care discourse, and the economic stability/prosperity of the country ⇒ Include a solid implementation plan, performance indicators, evaluation (demonstrate success) ⇒ Consider a business case to support development of a national, comprehensive caregiver strategy 	<p>Caregiver participants:</p> <ul style="list-style-type: none"> • Administrative assistance in preparing reports that may be presented to government regarding new/change policies <p>Researchers/Experts:</p> <ul style="list-style-type: none"> • Janet Fast, researcher: provide evidence (synthesis of existing; creation of new to fill gaps); develop business case for policymakers <p>Governments:</p> <ul style="list-style-type: none"> • Nova Scotia Department of Health and Wellness: share program information, etc. • Seniors and Health Aging Secretariat, Province of Manitoba

<p>Clear ask/story:</p> <ul style="list-style-type: none"> • Develop a concrete ask that is realistic and doable <ul style="list-style-type: none"> ⇒ Establish a secretariat to create positions and proposals ⇒ Change the language so that caregiver needs are not considered solely as a health file (cut across departments and sectors) ⇒ Reinforce that caregiver support is apolitical ⇒ Focus on equity (cross P/T parity of financial supports) 	<p>Patient/consumer groups:</p> <ul style="list-style-type: none"> • Ontario Parents Advocating for Children with Cancer: policy development
<p>Advocate/educate:</p> <ul style="list-style-type: none"> ▪ Related to above, establish task force or sub-committee or secretariat to define/outline/propose/advocate ▪ Approaches: <ul style="list-style-type: none"> ⇒ Target politicians, voters, health-care providers and stakeholders ⇒ Collaborate across governments, F/P/T and municipal, and sectors ⇒ Connect with F/P/T committees and task forces ⇒ National communications strategy with local twist; engage champions ⇒ Focus bottom up (advocates promote to provincial ministers/deputies) <i>and</i> top down (business case on federal Health Minister’s table for discussion) ⇒ Consider working with 1 or 2 provincial champions and disseminate learnings and evidence widely ⇒ Which pieces match which opportunities? i.e., are some pieces perfect for an election platform? Budget? Throne Speech? Department? 	<p>Patient/consumer groups:</p> <ul style="list-style-type: none"> • MHCC: incorporate the broad “asks” and policy change messages in our presentations and meetings with all levels of government – when we present on caregiver guidelines • MS Society: to help with government relations and advocacy – lobbying with government and agencies <p>Caregiver organizations/service providers:</p> <ul style="list-style-type: none"> • Manitoba Caregiver Coalition: see Caregiver Recognition Act into action <p>Health professional associations:</p> <ul style="list-style-type: none"> • CMA: for advocacy in collaboration with other stakeholders <p>Governments:</p> <ul style="list-style-type: none"> • Canada Revenue Agency Benefit Programs Directorate; Manager, Disability Tax Measures; Manager, DRC Program: “to help policy” • Employment and Social Development Canada, Seniors Policy: “balancing work and care policy priority”
<p>Explore new policy development:</p> <ul style="list-style-type: none"> ▪ Suggestions include: <ul style="list-style-type: none"> ⇒ Expand Health Canada services to First Nations for palliative care; cover palliative care medications on reserve; and cover housing costs when travelling for palliative care. ⇒ For others in rural and remote locations, make travel costs for hotel, gas and meals tax deductible, allowing quarterly applications based on tax paid to date. 	<p>Patient/consumer groups:</p> <ul style="list-style-type: none"> • Ontario Parents Advocating for Children with Cancer: policy development

- ⇒ Ensure any federal caregiver allowance is based on income threshold *and* adjusted for geography (remote, rural)
- ⇒ Increase the medical tax benefit to include non-medical services (transportation to appointments, direct home care services, respite care).
- ⇒ Have a menu of policy options for financial and respite supports (not all caregivers need the same thing).
- ⇒ Canada Health and Social Transfer funding increase to include home care and caregiver supportive care

MOVING FORWARD

STAKEHOLDER REFLECTIONS

Participants were asked the following question: *“Leaving this event, what are some actions you can do to contribute to this work?”*

Participant responses captured offers to help construct, recruit and/or serve on the National Task Force. Participants also offered to share the key messages and information stemming from the event through their networks and with their colleagues using vehicles such as social media and eNews. A number of participants noted that they would forward existing information and tools to inform the work ahead.



Participant contribution included:

Reaching out to employers and governments

- ⇒ “Invite provincial government to co-host a breakfast for employers/businesses where an organization with good practices is highlighted and speaks, encouraging other employers to do the same.”
- ⇒ “Talk to some of the corporate sponsors we already have relationships with to see if they support caregiving.”
- ⇒ “Bring together Manitoba partners present today and other key stakeholders to discuss ways we can work together to move this issue forward in MB. May include hosting an awareness event with employers on MB’s Caregiver Recognition Day.”
- ⇒ “Write to our provincial minister to advise of the meeting.”
- ⇒ “I have good relationships with policymakers, am developing them with employers, for network and advocacy/awareness-raising purposes.”

Summarizing/collating information

- ⇒ “Will send out information to our membership about this workshop, ask them to share information about reports, programs in their regions related to caregiver support and forward to you.”
- ⇒ “I will be making a suggestion/recommendation to the areas in the Canada Revenue Agency who promote tax credit programs to bundle the communications on caregiver-related tax credit programs together.”
- ⇒ “Work with caregiver association to compile directory of Department of Health & Wellness and Department of Community Services resources to increase access by caregivers and increase awareness.”



Research

- ⇒ “Currently writing two knowledge syntheses around economic costs of care and employment costs more specifically, one of which includes a policy scan; also developing new grant proposal to continue filling knowledge gaps re: economic costs of care.”
- ⇒ “I know most of the other researchers engaged on this topic so we can connect to a wider network/body of evidence.”
- ⇒ “Provide research support on areas of interest in moving activities forward (e.g., scans across provinces and territories, research on funded activities supported by Health Canada)”
- ⇒ “Provide analytics and other data to inform priority setting, resource lists, etc.”
- ⇒ “Currently, the Manitoba Caregiver Coalition is beginning a journey of workplace. Survey has been done of 2 leading businesses: MB Blue Cross and Lotteries. This will then be shared with focus groups of business members/communities to help them develop ways to support caregivers in the workplace.”



NEXT STEPS

In her closing comments, Marjorie Morrison, Chief Executive Officer of CCAN, reiterated the organization's commitment to working with stakeholders in helping to alleviate the financial burden on caregivers.

The Canadian Cancer Action Network, currently comprised of more than 85 patient-centred organizations from across Canada, is positioned to ensure a coordinated caregiver perspective informs the agenda and advances the work.

Through the CCAN network, the organization can act as a catalyst and facilitator with the broader stakeholder community. The forum was an important step towards broader pan-Canadian collaboration to address the financial hardships facing so many of Canada's caregivers.

In 2014, the focus of CCAN will be to convene a National Task Force on Family Caregivers in Canada to continue national dialogue and action.

Ms. Morrison thanked the participants for making the forum a very productive meeting.

APPENDICES

Appendix A: Agenda

Appendix B: Participant List

Appendix C: Sample Initiatives

Appendix D: Meeting Evaluation

Appendix E: About the Partners

APPENDIX A: AGENDA

Canada, a Caring Society: Action Table on Family Caregivers

Tuesday, October 22, 2013

The Lord Elgin Hotel (Macdonald Meeting Room) / Ottawa, Ontario

AGENDA

Time	Agenda Topic	Speaker
8:00am	REGISTRATION OPENS	
8:30am	Breakfast	
9:00am	Welcome and introductions	
9:05am	Agenda review	<i>Leslie Greenberg, Facilitator</i>
9:10am	Video presentation: <i>A Caregiver's Story</i>	Featuring <i>Teresa Solta</i> (Manitoba)
9:15am	Keynote presentation: <i>Recommendations of Reports from the Event Partners</i>	<i>Dr. Ella Amir</i> Member, MHCC Advisory Council and Executive Director, AMI-Quebec
9:35am	Introduction to breakout sessions	<i>Leslie Greenberg, Facilitator</i>
9:40am	Concurrent breakout sessions: <ol style="list-style-type: none"> 1. <i>Enhance awareness of caregiver financial burden</i> 2. <i>Improve access to resources/support services</i> 3. <i>Create more flexible workplace environments</i> 4. <i>Adapt/adopt government support programs</i> 	
10:30am	HEALTH BREAK	
10:45am	Breakout sessions (continued)	
12:00pm	LUNCH	
1:00pm	Plenary: <i>Gallery Walk</i>	<i>Leslie Greenberg, Facilitator</i>
2:15pm	Closing remarks	<i>Marjorie Morrison, Chief Executive Officer</i> Canadian Cancer Action Network
2:30pm	Event concludes	



APPENDIX B: PARTICIPANT LIST

Carolyn Allaby Maxwell

Director, Liaison & Service Support
Nova Scotia Department of Health and Wellness
carolyn.maxwell@gov.ns.ca

Ella Amir

Executive Director
AMI-Québec
ellaamir@amiquebec.org

Sharon Baxter

Executive Director
Canadian Hospice Palliative Care Association
sbaxter@bruyere.org

Odette Beaudoin

Caregiver Advisory Committee
obeaudoin46@gmail.com

Nicole Beben

VP, Knowledge and Care Exchange Programs
Saint Elizabeth
nbeben@saintelizabeth.com

Wendy Bell

Caregiver Advisory Committee
wendy_l_bell@yahoo.com

Charles Bergeron

Manager, Public Engagement and Alliance
Development
Canadian Medical Association
charles.bergeron@cma.ca

Angus Campbell

Executive Director
Caregivers Nova Scotia
director@caregiversns.org

Shubie Chetty

Senior Nurse and Quality Consultant
Home and Community Care, Health Canada
shubie.chetty@hc-sc.gc.ca

Shelly Cory

Executive Director
Canadian Virtual Hospice
shelly@virtualhospice.ca

Erin Crawford

Senior Director, Public Issues and Community
Engagement
Canadian Cancer Society, MB Division
ecrawford@mb.cancer.ca

Julie Donaldson

President
Manitoba Caregiver Coalition
julie.donaldson@homeinstead.com

France Dubé

Director, National Stakeholders, Digital Government
Affairs, Atlantic Government Relations
Eli Lilly
dube_france@lilly.com

Janet Fast

Professor
Department of Human Ecology, University of
Alberta
janet.fast@ualberta.ca

Leslie Greenberg

Leslie Greenberg Consulting
leslie_g@bell.net

Helene Hardy

Caregiver Advisory Committee
helene.hardy@gmail.com

Jacquelin (Jackie) Holzman

Chair
Canadian Cancer Action Network
jackiefh@rogers.com

Kellie Huffman

Caregiver Advisory Committee
redplaid@shaw.ca

Pam King

Chair
CCAN Manitoba
pkking@mts.net

Francine Knoops

Lead, Strategic Policy and Stakeholder
Engagement
Mental Health Commission of Canada
fknoops@mentalhealthcommission.ca

Shannon Kohler

Consultant
Manitoba Seniors & Healthy Aging Secretariat
shannon.kohler@gov.mb.ca

Sandra Levinson

Caregiver
sandra@levinson.ca

Georgia Livadiotakis

Senior Policy Analyst
Health Canada
georgia.livadiotakis@hc-sc.gc.ca

Penny MacCourt

Research Affiliate
University of Victoria, Centre on Aging
pennymaccourt@shaw.ca

Sandra MacLeod

Senior Policy Analyst
Seniors Policy Division, Employment and Social
Development Canada
sandra.macleod@hrsdc-rhdcc.gc.ca

Anna Mann

Executive Director
Alberta Caregivers Association
amann@albertacaregivers.org

Jenn McNeil Gordon

Operations Manager
Canadian Breast Cancer Network
jmcneil@cbcn.ca

Dan Mornar

Patient/Parent Advocate
Oncology/Hematology/BMT Program
BC Children's Hospital
dmornar@cw.bc.ca

Marjorie Morrison

Chief Executive Officer
Canadian Cancer Action Network
mmorrison@canceraction.ca

Denise Page

Senior Policy Analyst
Canadian Cancer Society, National Public Issues
Office
dpage@cancer.ca

Eugene Paquin

Board Member
MS Society of Canada, Saskatchewan Division
epaquin@shaw.ca

Tonya Price

Manager, Disability Programs
Canada Revenue Agency
tonya.price@cra-arc.gc.ca

Bonnie Schroeder

Director
Canadian Coalition for Seniors' Mental Health
director@ccsmh.ca

Ryan Smith

Senior Policy Analyst
Employment and Social Development Canada
ryan.t.smith@hrsdc-rhdcc.gc.ca

Mark Stolow

Director
Caring Voice Network
mark@careringvoice.com

Lori Synes Taraba

Caregiver Advisory Committee
stevet@niagara.com

James Thomson

Community Engagement & Resource
Development Coordinator
Ontario Parents Advocating for Children with
Cancer
engagement@opacc.org

Stephen Vail

Director, Research and Policy Development
Canadian Medical Association
steve.vail@cma.ca

Nicholas Watters

Director, Knowledge Exchange Centre
Mental Health Commission of Canada
nwatters@mentalhealthcommission.ca

Adam Waiser

Senior Analyst, Public Issues
Canadian Cancer Society, National Public Issues
Office
Adam.Waiser@cancer.ca

Liz Wigfull

Knowledge Broker
Mental Health Commission of Canada
lwigfull@mentalhealthcommission.ca

Allison Williams

Associate Professor, CIHR Research Chair in
Gender, Work and Health
School of Geography & Earth Sciences, McMaster
University
awill@mcmaster.ca

APPENDIX C: SAMPLE INITIATIVES

Compiled through a review of reports released by the event partners, as well as participants' feedback onsite and via a pre-forum survey¹⁹.

ENHANCE AWARENESS OF CAREGIVER FINANCIAL BURDEN

Caregivers are Not Superheroes Campaign: in honour of Caregivers' Week in Quebec (November 2-8, 2009), the [Care-Ring Voice Network](#) launched this campaign to reinforce that caregivers are not superheroes and require better support and assistance. In partnership with the pharmacy Uniprix, the bilingual campaign included print material, a micro site, and a public service announcement.

The Seniors & Healthy Aging Secretariat in Manitoba has developed an interdepartmental working group to assist with the implementation of the new [Caregiver Recognition Act](#) and identify solutions to caregiver issues including financial burdens. The purposes of the Act are to: a) increase recognition and awareness of caregivers; b) acknowledge the valuable contribution they make to society; and c) help guide the development of a framework for caregiver recognition and caregiver supports.

The Manitoba Government has proclaimed the first Tuesday of April in each year as [Caregiver Recognition Day](#) (a component of the Caregiver Recognition Act). The Caregiver Recognition Day is an opportunity to: a) celebrate the efforts of informal caregivers of all ages; b) raise awareness of informal caregiver issues; c) empower informal caregivers with information; and d) increase support for informal caregivers.

The first Tuesday in April is designated as National Caregiver Day in Canada. The aim is to raise public awareness of social and economic value of unpaid work, and recognize family caregivers and their selfless commitment to helping their loved ones. A number of organizations, such as the Canadian Hospice Palliative Care Association and the Canadian Caregiver Coalition leverage this day to reach caregivers and/or spark greater public awareness.

The [Champion's Council](#) of the Canadian Hospice Palliative Care Association is comprised of a group of key leaders in Canada who lend their voice and advance the profile of hospice palliative care issues, including workplace considerations.

IMPROVE ACCESS TO RESOURCES/SUPPORT SERVICES

The pre-forum survey and event partners' reports reference a number of organizations and Web sites that provide information, education and other resources to caregivers, including detail on existing financial support programs.

Among them, the [Family Caregiving for People at the End of Life](#) Web site offers information about government benefit plans, tax credits, funding sources or housing renovation grants available across Canada. Other sites include [the Canada Mortgage and Housing Corporation](#), [Canadian Virtual Hospice – Financial Benefits](#), [Caregiver-Connect \(VON Canada\)](#), and [The FamilyCaregiver.com](#).

In terms of specific financial resources, the support group AMI-Québec developed the guide [Sharing the Care: Financial and Legal Considerations in Planning for People with Mental Disabilities in Quebec](#) to assist family caregivers in their plans to secure the future of an ill relative.

National organizations, such as the Canadian Home Care Association and the Canadian Hospice Palliative Care Association, produce reports and offer information and resources for caregivers.

Likewise, regional caregiver organizations (e.g., Caregivers Nova Scotia, the Family Caregivers' Network Society in Victoria, B.C.) provide tools (e.g., handbooks, videos) and other support for caregivers. For instance, the [Caregivers Out of Isolation](#) program (Seniors Resource Centre of Newfoundland and Labrador) offers a toll-free caregiver line, referrals, newsletters and guides, networks, and support groups.

Regional home care organizations and home care service providers also provide clients with information on accessing community resources and support services, as do hospitals related to discharge. Caregivers can speak with qualified health professionals via the Saint Elizabeth [Ask Elizabeth Support Line](#), for example, to obtain information and resource support.

The [Pediatric Interlink Community Nursing Program](#) is offered by the Pediatric Oncology Group of Ontario (POGO), and funded via Ministry of Health and Long-Term Care (MOHLTC). Interlink nurses facilitate navigation of the health-care system for families, helping them to locate and access community and hospital resources.

Outside Canada, [Carers UK](#) is a charity set up to help the millions of people who look after an older, disabled or seriously ill family member or friend. Their initiatives raise both public and policymakers' awareness of caregiver contributions, challenges and needs.

The partner reports and participants also highlighted some ways corporate sponsors, community organizations and others are providing direct assistance to caregivers.

The British Columbia Childhood Cancer Parents Association, a registered non-profit charitable society, works with the BC Children's Hospital and the Surrey Memorial and Victoria General's Pediatric Oncology Departments to help families in need through their [Family Financial Aid Program](#).

The Pediatric Oncology Group of Ontario (POGO), a non-profit, multi-disciplinary collaboration representing the pediatric programs in Ontario that treat children with cancer, reimburses families for some out-of-pocket expenses they incur while a child is in treatment (e.g., accommodation, food, child care) via the [POGO Financial Assistance Program](#). Coast to Coast Against Cancer Foundation is the lead sponsor.

Getting transportation to treatment: In certain regions, patients registered with the [Canadian Cancer Society \(CCS\) transportation service](#) will be picked up and taken to/from their cancer treatment appointment by a volunteer driver. For new patients over 18, there is now a one-time \$100 registration fee; those unable to pay the full registration fee may be eligible for assistance through the CCS compassionate program.

[Give-a-Mile](#) funds air transportation through micro donations of air miles; Little Angels (U.S.) – private planes and pilots who offer patients trips to hospitals and home

CREATE MORE FLEXIBLE WORKPLACE ENVIRONMENTS

In 2010, VON Canada (Victorian Order of Nurses) released a [publication](#)²⁰ outlining ways employers are already supporting caregivers in the workplace, and how Canadian employers might get started in creating caregiver-friendly workplaces. The publication highlights the following Canadian employers, recognized for their leadership in the workplace.

The Home Depot and TELUS Corporation are on the list of Canada's Top 100 Employers for 2011 in part for their flexible work arrangement options.

KPMG was recognized as one of Canada's Top 100 Employers in 2011 for offering up to 80 hours of emergency dependent care each year, which includes spousal and elder care.

Bayer was listed among Canada's Top 100 employers in 2011 in part for topping up to 100% the salaries of those on compassionate leave for a period of eight weeks.

VON Canada uses its Katherine Pearson Caregiver Award to recognize an employee or volunteer who is balancing work and caregiving responsibilities, acting as an example for others.

There is a range of information available to support caregivers, which can be used by employers. Two examples are the Care-Ring Voice tele-learning support network available to caregivers in a number of provinces, and the VON's Caregiver Connect Web site which is available to all Canadians.

Other initiatives, identified through the pre-forum online survey:

The Province of Manitoba (as an employer) held a series of focus groups with employed caregivers and based on their feedback has created a plan to increase workplace supports for caregivers.

As the Patient/Parent Advocate for Oncology at the BC Children's Hospital, it is often my role to engage employers around special considerations for an employee of theirs who has a child with cancer.

A "donated sick leave policy" allows employees' accrued sick leave to be donated to a leave pool for sharing with caregiver employees in certain circumstances.

The Canada Revenue Agency permits employees to take family-related leave in order to care for family members.

CSSS Cavendish workplace/caregiving analysis and RAANM (Regroupement des aidants et aidantes naturels de Montréal) workplace policy review.

[Employers for Carers](#), a UK initiative that evolved from a group of employers committed to working carers, is chaired by British Gas and supported by the specialist knowledge of Carers UK. Their key purpose is to ensure that employers have the support to retain employees with caring responsibilities.

ADAPT/ADOPT GOVERNMENT SUPPORT PROGRAMS

Employment Insurance (EI) provides [Compassionate Care Benefits](#) to those who have to be away from work temporarily to provide care or support to a family member who *is gravely ill with a significant risk of death*. Self-employed people who register for the EI program may also be eligible to receive compassionate care benefits.

A [Family Caregiver Tax Credit](#) is available to individuals who support dependants with impairments in physical or mental functions. The credit is a \$2,000 enhancement to amounts already available under existing dependency-related non-refundable credits, including the: a) spouse or common-law partner amount; b) amount for an eligible dependant; c) amount for children born in 1995 or later; and d) caregiver amount.

The Canada Pension Plan [Child-Rearing Provision](#) permits eligible workers to exclude from the calculation of pensionable earnings the years when they stopped work or had lower earnings while they had a child under age seven, ensuring they get the highest possible payment.

A parent who has to be away from work to provide care or support to a critically ill or injured child may be eligible for [EI special benefits for Parents of Critically Ill Children](#) (PCIC). The benefit is up to a maximum of 35 weeks during a 52-week window if the parent has to be absent from work to provide care or support to a critically ill or injured child. A parent can also apply for the PCIC benefit if unemployed and already receiving EI benefits.

The [Registered Disability Savings Plan](#) (RDSP) helps Canadians with disabilities and their families save for the future. Earnings accumulate tax-free until the money is taken out of the RDSP. Parents or guardians may open an RDSP for a minor. With written permission from the holder, anyone can contribute to the RDSP.

Manitoba's [Primary Caregiver Tax Credit](#) provides a refundable credit of up to \$1,275 a year to people who act as primary caregivers for spouses, relatives, neighbours or friends who live at home in Manitoba. Caregivers may earn the credit for up to three care recipients at any given time. This means the maximum credit for a caregiver looking after three care recipients throughout a full year (after a three-month qualifying period for each care recipient) is \$3,825 (Manitoba Finance).

Quebec offers a refundable tax credit ([Tax Credit for Caregivers](#)) paid to an individual who houses an eligible relative without being remunerated for doing so and who provides the relative with continuous care and assistance. The tax credit may be up to \$700 for each relative being housed (Revenu Quebec).

The **Nova Scotia** Department of Health and Wellness offers a [Caregiver Benefit](#) that targets “low income care recipients who have a high level of disability or impairment as determined by a home care assessment. If the caregiver and the care recipient both qualify for the program, the caregiver will receive the Caregiver Benefit of \$400 per month.” As well, the Department offers other [programs](#) that more indirectly benefit caregivers, such as Facility-Based Respite Care and Self Managed Care.

Caregiver compensation programs in Nova Scotia, UK, Australia, etc; pension protection in several European countries; right to request flexible work arrangements in UK, Australia & human rights case law developing around this in Canada.

Federal and provincial documents - some of which are publicly available. Finance Canada, Parliamentary Budget Officer's report on seniors.

APPENDIX D: MEETING EVALUATION

Of forty-one (41) participants, there were ten (10) evaluation respondents.

Nine-in-ten respondents either agreed or strongly agreed that they were satisfied with the outcomes of the meeting. All of the respondents agreed or strongly agreed that the meeting purpose and objectives were clearly stated, adequate background information was provided and they were encouraged to participate and express their views.

In the written comments, positive aspects of the meeting most often mentioned were the networking, followed by the breakout sessions and speaker. In terms of areas for improvement, most often mentioned was that more meeting time was required for reflection and prioritizing issues.

The evaluation feedback is outlined below. The numbers in the chart represent the proportion of responses to each question (out of ten).

Canada, a Caring Society: Action Table on Family Caregivers Meeting Evaluation Form

Please indicate how much you agree with the following statements by circling your response using the scale provided: **1 = strongly disagree / 5 = strongly agree**

	Strongly disagree	D	N	A	Strongly agree
<i>The meeting purpose and objectives were clearly stated</i>				1/10	9/10
<i>Adequate background information was provided</i>				2/10	8/10
<i>We shared decision-making at this meeting*</i>		1/10	1/10	3/10	4/10
<i>I was encouraged to participate and express my views</i>				1/10	9/10
<i>Overall, the discussion remained focused and on track</i>			1/10	3/10	6/10
<i>I am satisfied with the outcomes of this meeting</i>			1/10	3/10	6/10
<i>Our meeting time was convenient for me</i>				1/10	9/10
<i>Our meeting place was convenient for me</i>				2/10	8/10
<i>I leave the meeting today feeling energized and positive</i>			3/10		7/10
What aspects of this meeting were particularly good?					
<ul style="list-style-type: none"> Comments focused on: networking and dialogue; Dr. Amir’s discussion; event structure and facilitation. 					
How could this meeting have been improved?					
<ul style="list-style-type: none"> The primary suggestions centered on allowing for more meeting time (e.g., two days). Other comments included ensuring greater representation (e.g., McConnell) and further prioritizing areas of focus. 					
Additional comments:					
<ul style="list-style-type: none"> Many thanked the organizers for convening stakeholders around this issue. Others expressed the importance of continued networking and action post-forum (“follow up critical!). One person noted that the policy board focused on how to advance the ‘asks’ and not the specific asks themselves. 					

* One responded considered the question ‘not applicable’ to this event

APPENDIX E: ABOUT THE PARTNERS

Canadian Cancer Action Network (Project Lead)

The Canadian Cancer Action Network, a national volunteer-driven organization comprised of diverse patient-centred organizations from across Canada, is dedicated to ensuring a coordinated patient and caregiver perspective is firmly embedded in work across the cancer control continuum.

Canadian Cancer Society

The Canadian Cancer Society is a national community-based organization of volunteers whose mission is the eradication of cancer and the enhancement of the quality of life of people living with cancer.

Canadian Caregiver Coalition

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.

Canadian Partnership Against Cancer (Project Funder)

The Canadian Partnership Against Cancer works with Canada's cancer community to reduce the burden of cancer on Canadians. Grounded in and informed by the experiences of those affected by cancer, the organization works with partners to support multi-jurisdictional uptake of evidence that will help to optimize cancer control planning and drive improvements in quality of practice across the country. Through sustained effort and a focus on the cancer continuum, the Partnership supports the work of the collective cancer community in achieving long-term population outcomes: reduced incidence of cancer, less likelihood of Canadians dying from cancer, and an enhanced quality of life of those affected by cancer.

Mental Health Commission of Canada

The Mental Health Commission of Canada is a catalyst for change. We are collaborating with hundreds of partners to change the attitudes of Canadians toward mental health problems and to improve services and support. Our goal is to help people who live with mental health problems and illnesses lead meaningful and productive lives. Together we create change. The Mental Health Commission of Canada is funded by Health Canada.

Endnotes

-
- ¹Fast J, Lero D, Duncan K, et. al. *Employment consequences of family/friend caregiving in Canada*. Edmonton: Research on Aging, Policies and Practice, University of Alberta, 2011.
- ²Chappell, N., Havens, B., Hollander, M., Miller, J. and McWilliams, C. (2004). "Comparative Costs of Home Care and Residential Care." *The Gerontologist* 44(3): 389- 400.
- ³Study, Caregivers in Canada: 2012; <http://www.statcan.gc.ca/daily-quotidien/130910/dq130910a-eng.htm>
- ⁴Tsimicalis, A. Costs Incurred by Families of Children Newly Diagnosed with Cancer in Ontario. University of Toronto, 2010.
- ⁵[The Financial Hardship of Cancer in Canada: A Call for Action](#), CCAN/CCS (Manitoba divisions), 2012; [A Framework for a Canadian Caregiver Strategy](#), CCC, 2008; [National Guidelines for a Comprehensive Service System to Support Family Caregivers of Adults with Mental Health Problems and Illnesses](#), MHCC, 2013
- ⁶Fast J, Lero D, Duncan K, et. al. *Employment consequences of family/friend caregiving in Canada*. Edmonton: Research on Aging, Policies and Practice, University of Alberta, 2011.
- ⁷Chappell, N., Havens, B., Hollander, M., Miller, J. and McWilliams, C. (2004). "Comparative Costs of Home Care and Residential Care." *The Gerontologist* 44(3): 389- 400.
- ⁸Canadian Hospice Palliative Care Association, *Valuing Caregiving and Caregivers: Family Caregivers in the Integrated Approach to Palliative Care*, The Way Forward initiative: an Integrated Palliative Approach to Care, 2013
- ⁹Tsimicalis, A. Costs Incurred by Families of Children Newly Diagnosed with Cancer in Ontario. University of Toronto, 2010.
- ¹⁰Health Canada. (2002). *National profile of family caregivers in Canada*
- ¹¹Canadian Caregiver Coalition. www.ccc-ccan.ca
- ¹²Fast et al, 2011
- ¹³10th Annual Health Care in Canada Survey: A national survey of health care providers, managers, and the public, 2007, <http://www.hcic-sssc.ca>
- ¹⁴Mental Health Commission of Canada. (2012). *Changing directions, changing lives*.
- ¹⁵Dupuis, S., Epp, T., & Smale, B. (2004). *Caregivers of persons with dementia: roles, experiences, supports, and coping: a literature review*. Waterloo, Ontario: Murray Alzheimer Research and Education Program, University of Waterloo.
- ¹⁶Canadian Hospice Palliative Care Association, *Valuing Caregiving and Caregivers: Family Caregivers in the Integrated Approach to Palliative Care*, The Way Forward initiative: an Integrated Palliative Approach to Care, 2013. [<http://hpcintegration.ca/media/37049/TWF-valuing-caregivers-report-final.pdf>]
- ¹⁷MacCourt P., Family Caregivers Advisory Committee, Mental Health Commission of Canada. (2013). *National Guidelines for a Comprehensive Service System to Support Family Caregivers of Adults with Mental Health Problems and Illnesses* Calgary, AB: Mental Health Commission of Canada. Retrieved from: <http://www.mentalhealthcommission.ca>
- ¹⁸Torjman, S., & Makh, A. (2010) Caregivers and Dementia. *Maytree Policy in Focus*, 11. Retrieved November 2012 from: <http://maytree.com/policyPDF/MaytreePolicyInFocusIssue11.pdf>
- ¹⁹Question: are you aware of any activity or successful initiatives in these areas that can be expanded or applied more broadly across Canada?
- ²⁰Meredith B. Lilly, *Curtailing the Cost of Caring for Employers and Employees: What Every CEO Should Know*, November 2010, VON Canada