

# Ontario Caregiver Coalition

## *Advancing the Interests of Caregivers in Ontario*

### Policy Options for Inclusion in the 2009 Budget November 2008

The Ontario Caregiver Coalition (OCC) is a newly-formed coalition dedicated to bringing issues related to caregiving to the policy table. The OCC is pleased to provide its perspective and recommendations on the 2009 Ontario Budget.

For the purposes of its work, the Ontario Caregiver Coalition endorses the definition of caregiver used by the Canadian Caregiver Coalition. Caregivers discussed in this document are “...individuals who provide care and assistance for their family members and friends who are in need of support because of physical, cognitive or mental health conditions.”<sup>1</sup> These individuals are referred to as “caregivers” or “family caregivers” throughout this document.

Family caregivers supplement and complement Canada's health care system. In 2001 it was estimated that about three million Canadians were informal caregivers, delivering about \$5 billion worth of service to Canada's economy and saving Canada's formal health system as much as \$2 billion per year.<sup>2</sup> Caregivers provide more than 80% of the care needed by individuals with long term health conditions. It is difficult to imagine what Canada's – and Ontario's – health care system would look like without the support of these caregivers.

Caregivers are at risk for significant health problems and stress, despite enjoying the inherent satisfaction of caring for their loved ones.<sup>3</sup> In particular, depression

<sup>1</sup> Canadian Caregiver Coalition. Framework for a Canadian Caregiving Strategy. 2004. Page 1.

<sup>2</sup> Fast, Eales and Keating. Economic Impact of Health, Income Security and Labour Policies on Informal Caregivers of Frail Seniors. Ottawa: Status of Women Canada. 2001. [www.swc-cfc.gc.ca](http://www.swc-cfc.gc.ca)

<sup>3</sup> Whitlatch, C.J., Feinberg, L.F., & Sebesta, D.S. (1997). Depression and health in family caregivers. *Journal of Aging and Health*, Vol.9 (2), 222-243.

[http://caregiver.org/caregiver/jsp/content\\_node.jsp?nodeid=1822](http://caregiver.org/caregiver/jsp/content_node.jsp?nodeid=1822)

#### Active Partners

Alzheimer Society of Ontario  
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MS Society of Canada, Ontario

Ontario Community Support Association

Providence Centre

Ontario Home Care Association

Saint Elizabeth Health Care

Ontario Association of Community Care Access Centres

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and psychological illnesses trouble caregivers with increasing intensity as the years of caregiving lengthen<sup>4</sup>. Research has shown that more than one third of caregivers continue to provide intense care to others while suffering from poor health themselves.<sup>5</sup> Consequently, caregivers frequently succumb to illness, rendering them no longer capable of providing care to their loved one, and often necessitating placement of the loved one in a hospital or long-term care facility.

The contributions of family caregivers is critical in the light of health human resource shortages. Ontario has come to rely heavily on family caregivers who support family members and friends across the provincial health care system. Family caregivers are involved in providing care at the community, in long term care homes<sup>6</sup> and increasingly, in hospitals. Researchers are beginning to ask if these demands are reasonable, and if we can continue to expect the same level of dedication and care into the future.<sup>7</sup> It is recognized that social trends (like family breakdown, family separation and parent-child alienation) put the continuity of family caregiving at risk.<sup>8</sup>

With rising costs of the health system, escalating health human resource shortages, and a growing aging population, the continuing contribution of family caregivers is essential.

To better support caregivers, the Ontario Caregiver Coalition recommends that the Government of Ontario consider the following principles and recommendations outlined in the following pages.

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<sup>4</sup> Grunfeld, E. (2004). Family caregiver burden: Results from a longitudinal study of breast cancer patients and their principal caregivers. *Canadian Medical Association Journal*, 170(12): 1795-1801.

<sup>5</sup> Navaie-Waliser, M., Feldman, P.H., Gould, D.A., Levine, C.L., Kuerbis, A.N. & Donelan, K. (2002). When the caregiver needs care: The plight of vulnerable caregivers. *American Journal of Public Health*, 92(3), 409-413. [http://caregiver.org/caregiver/jsp/content\\_node.jsp?nodeid=1822](http://caregiver.org/caregiver/jsp/content_node.jsp?nodeid=1822)

<sup>6</sup> The Glue that Bind: Family Caregivers Provide Facility Based Geriatric Care. As cited in Home and Community Care Highlights. Volume 7, No 2: June 2008.

<sup>7</sup> Home and Community Care Digest. Vol 7 No 2 2008. Are we exoecting too much from family caregivers? <http://www.longwoods.com/product.php?productid=19906>

<sup>8</sup> Fast, Eales and Keating. Economic Impact of Health, Income Security and Labour Policies on Informal Caregivers of Frail Seniors. Ottawa: Status of Women Canada. 2001. [www.swc-cfc.gc.ca](http://www.swc-cfc.gc.ca)

**Principle #1: Prioritize Caregiving Issues to support caregivers today and into the future.**

It is evident that the Government of Ontario understands the significant contributions of family caregivers. This was demonstrated in the 2007 Speech from the Throne which highlighted: the importance of “volunteers who take on the thankless tasks,” ; the need for Ontario “to build a strong and caring society,” : and the initiation of “a caregiver grant for those caring for elderly family members.”<sup>9</sup> Similarly, the *Caring About Caregivers* consultations currently being conducted by the Ministry of Health and Long-Term Care show that the government recognizes the important role that family caregiving plays in our health care system. The Ontario Caregiver Coalition applauds these actions.

The contributions of family caregivers will become even more critical to Ontario’s sustainability. An aging population, limited health human resources and constrained finances will put pressure on Ontario’s health system over the next few decades. In order to maintain the system’s equilibrium, it will become increasingly important for government to encourage and promote family caregiving. To do this, the OCC suggests that government:

- **Recognize the importance of the family caregiver.** This does not have to be costly but this should be consistent across ministries and at all levels of government.

Examples	Benefits to the System	Implications for Caregivers
Enhance family care policies in the public service and broader public service.	<p>Integrated message to the public that families are valued by governments and that policies will be developed to support families.</p> <p>Complementary policies across all parts of government.</p>	<p>Recognition of caregiver role.</p> <p>Facilitated access to services that support caregivers in the workplace, in the housing market and in schools and universities.</p>

<sup>9</sup> Government of Ontario Speech from the Throne 39<sup>th</sup> Parliament, November 29, 2007.

- **Champion caregiver issues.**

Examples	Benefits to the System	Implications for Caregivers
Build on Canadian Caregiver Coalition initiatives in Ontario. Collaborate with federal colleagues, partner with other provinces.	Supports in place at all levels that encourage continuation of family caregiver role now and in the future.	Role of caregiver is recognized and rewarded through a set of consistent policies at both the federal and provincial levels.

**Principle #2: Expand Financial Incentives to help defray the cost of caregiving**

Family caregivers experience significant financial stress as a result of their caregiving commitments. In some instances, they must assume the direct costs of caring, like the costs of nursing services or medical supplies, as well as the indirect costs of caregiving such as loss of income. Many caregivers are forced to take unpaid leave of absence or leave the workforce because of caregiving demands.<sup>10</sup>

Some financial assistance is available to caregivers at the present time. The Ontario Government provides caregiver tax credits (maximum claim of \$4,031 reduced by dependant's net income in excess of \$13,792<sup>11</sup>), travel grants<sup>12</sup> and grants for physical modifications to the home<sup>13</sup>, however these benefits are limited and access may be limited by restrictive eligibility criteria.

The Ontario Caregiver Coalition is aware that the current economic environment limits the capacity of governments to undertake new programs over the next few years. For this reason the Ontario Caregiver Coalition suggests that the Government of Ontario consider the following:

- **Work with the Ontario Caregiver Coalition to examine a range of options that will provide financial support to family caregivers in Ontario.**

<sup>10</sup> Health Canada. National Profile of Family Caregivers in Canada – Final Report. 2002. [www.hc-sc.gc.ca](http://www.hc-sc.gc.ca)

<sup>11</sup> Ontario Ministry of Finance. (2007) Ontario Outlook and Fiscal Review, Annex V: Transparency in Taxation, Table 2.

<sup>12</sup> Available to the caregiver for bus, train and plane travel if the physician determines that the care recipient cannot travel alone, and if the care recipient lives in a designated area more than 100 kilometers from where care will be dispensed. Travel grants for travel by car is shared between care recipient and caregiver and there is a 100 kilometer deductible.

<sup>13</sup> Available to the care recipient.

The Ontario Caregiver Coalition will work with the Ontario Government on a joint Task Force to identify and evaluate policy options that will provide financial incentives to caregivers.

Examples	Benefits to the System	Implications for Caregivers
Increase income tax deductions for caregiving, Raise income thresholds for tax credit benefits, increase the value of the tax credits.	Caregivers continue to provide care to loved ones.	Caregivers are compensated for direct and indirect costs of caregiving.

**Principle #3: Continue emphasis on enhanced health and social services for care recipients and care givers**

The Ontario Caregiver Coalition recognizes that Ontario has already begun to build a foundation of supports for family caregivers. Most recently this support has been evident in the Aging at Home Strategy, announced August 2007. This strategy is an important step in expanding a continuum of services which allow seniors to stay at home.

In many ways the success of the Aging at Home strategy is contingent upon the willingness and availability of family caregivers to support their loved ones in the community. Not only do family caregivers provide instrumental support to their loved ones, but they also coordinate services, communicate with health providers, monitor health status, and provide social and emotional support to the care recipient. If caregivers are not available to support seniors at home, the success of the strategy is at risk. Research recently completed by the Canadian Research Network for Care in the Community (CRNCC), recognized the vital role of caregivers in keeping people at home and diverting hospital and long term care home costs.<sup>14</sup> (In fact this research suggests that when considering home and community care, one must view the unit of care as the service to the "individual and carer".<sup>15</sup>)

An analysis of Local Health Integration Network (LHIN) Aging at Home Directional Plans and Year 1 and Year 2 Priorities undertaken by the Ontario Caregiver Coalition, indicates that LHINs across Ontario have recognized this

<sup>14</sup> A. Paul Williams. Look Globally, Act Locally: The Balance of Care in Ontario. Presentation at Integrating Care in the Community for Vulnerable Populations. Oct 20<sup>th</sup>, 2008.

<sup>15</sup> Ibid. Slide 43.

reality.<sup>16</sup> Virtually all LHINs have articulated and/or acted upon their intent to develop programs and services specifically to support caregivers in their caregiving roles. Some LHINs have chosen to enhance respite care and adult day services, while others have implemented caregiver support networks to provide direct support (information, counselling, etc.) to family caregivers.<sup>17</sup>

The Ontario Caregiver Coalition applauds these initiatives and innovations, and recommends that the Ontario Government continue to emphasize the importance of providing caregiver support to the LHINs and to the rest of the health care system.

The Aging at Home Strategy was designed to enhance care to seniors, but it does not address the needs of younger adults with disabilities, chronic illnesses and injuries. The Aging at Home Strategy was not designed and developed to support these individuals. The Ontario Caregiver Coalition encourages the government to continue to build the continuum of care for all Ontarians, regardless of age.

The Ontario Caregiver Coalition recommends the following:

- **Continue implementation and funding of the Aging at Home Strategy**

Examples	System Benefits	Implications for Caregivers
Enhance access to a broad range of community support services, home care. Innovative programs to meet local needs	Helps seniors stay in the community for as long as possible. Diminishes the need for costlier levels of care. Enhances quality of life for seniors by supporting autonomy and community living.	Caregivers are supported in their caregiving role and are able to continue to provide care to loved ones longer.

<sup>16</sup> Ontario Caregiver Coalition. Strategic Inquiry Process. Analysis of Aging at Home Initiatives in Ontario's LHINs. 2008.

<sup>17</sup> Ibid.

- **Maintain and enhance community-based programs and services for all Ontarians who require them.**

Examples	System Benefits	Implications for Caregivers
Enhanced access to preventive care, rehabilitative care, social, and recreational opportunities, home care, community support services, supportive housing services and respite care.	Builds a continuum of care options in the community which facilitates aging in place for seniors, people with disabilities and people with chronic illnesses.	Caregivers have opportunities to rest, socialize and renew themselves so that they can stay healthy and continue to provide care to their loved ones.

- **Develop a consistent message around caregiver support to the LHINs, health care providers and policy makers.**

Examples	System Benefits	Implications for Caregivers
Enhanced access to caregiver education and caregiver relief programs Development of new services to support caregivers.	Contributes to system sustainability.	Caregivers are supported in their caregiving role.

#### **Principle #4: Facilitate access to information for caregivers**

A recent Ontario study conducted by the Alzheimer Society of Ottawa and Renfrew County, the Caledon Institute of Social Policy and the Champlain Dementia Network, has added to the already large body of evidence that shows that caregivers often do not have access to the information they need.<sup>18</sup> This research, which involved extensive consultations with caregivers, identified the need for caregivers to receive timely and appropriate information - about formal services, about how to provide care, and about how to navigate the system. This finding has been replicated through Stakeholder Engagement processes conducted by LHINs across the province. For this reason, the Ontario Caregiver Coalition suggests that the Government of Ontario:

<sup>18</sup> Tirhnan, S. and Makhoul, A. Caregivers and Dementia. Caledon Institute of Social Policy, Alzheimer Society of Ottawa and Renfrew County and Champlain Dementia Network. June 2008.

- **Establish an Expert Panel to examine how family caregivers receive and use information, and provide recommendations to government about how to meet the information needs of family caregivers.**

Examples	System Benefits	Implications for Caregivers
Examine results of research on caregiver information needs. Conduct round tables with caregivers (in conjunction with LHINs) to get input on how family caregivers prefer to receive and use information	Ontario based experts do research and compile best practices  System learning and application of best practices	Input into the policy development process  Programs and services designed to meet specific needs of Ontario family caregivers

- **Encourage existing information access initiatives to consider how to deliver information to family caregivers**

Examples	Benefits to System	Implications for Caregivers
Give family caregivers access to Chronic Disease patient portals (under development for diabetes). Develop caregiver information line in new 310-CCAC system	Facilitates access to health information and services.  Generates efficiencies by supporting patient & caregiver responsibility for care monitoring and decision making.	Caregiver recognized as part of the care team.  Caregiver supported in caregiving and care management roles.

In family caregivers, Ontario has a dedicated “shadow workforce”<sup>19</sup> which is critical to the continuing success of the health and social services delivery systems. This shadow workforce needs the recognition and the support of government to continue to play its caregiving role.

The Ontario Government has already flagged the need to start planning support services for caregivers. The new Long Range Scenario Planning (LSRP) exercise entitled *Caring About Caregivers* demonstrates that the Government is aware of the growing importance and needs of this population. The Ontario Caregiver Coalition applauds this initiative and its members are committed to continuing to participate in this process into the future.

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<sup>19</sup> Term coined by Alzheimer Society Ontario. *Caring for Caregivers: Alzheimer Society of Ontario's Reponse to the 2008 Pre-Budget Consultations*, January 31, 2008.

However, there is no need to wait for the outcome of this process to introduce caregiver support policies that will provide some immediate – and much needed – relief to caregivers. There is opportunity to begin the process of supporting caregivers now.

While a full continuum of caregiver support policies and programs would be ideal to allow caregivers the opportunity to choose the programs and services that best meet their needs, we understand that development of this continuum will take time. Therefore, the Ontario Caregiver Coalition suggests an incremental approach to building this continuum. By enhancing current caregiver support services and introducing some targeted new programs, the foundation of the continuum will be established. This foundation can then be enhanced and expanded gradually over the next decade.

With this submission, the Ontario Caregiver Coalition has identified its key recommendations for beginning to build this foundation. We look forward to partnering with you on these and other caregiver support initiatives.

## **Summary of overarching principles and recommendations:**

- 1. Prioritize Caregiving Issues to support caregivers today and into the future**
  - a. Recognize the importance of the family caregiver**
  - b. Champion caregiver issues**
  
- 2. Expand Financial Incentives to help defray the cost of caregiving**
  - a. Work with the Ontario Caregiver Coalition to examine a range of options that will provide financial support to family caregivers in Ontario.**
  
- 3. Continue emphasis on enhanced health and social services for care recipients and care givers**
  - a. Continue implementation of Aging at Home Strategy**
  - b. Maintain and enhance community-based programs and services**
  - c. Develop a consistent message around caregiver support to the LHINs, health care providers and policy makers.**
  
- 4. Facilitate access to information for caregivers**
  - a. Establish an Expert Panel to examine how family caregivers receive and use information, and provide recommendations to government about how to meet the information needs of family caregivers.**
  - b. Encourage existing information access initiatives to consider how to deliver information to family caregivers**