

**ALZHEIMER SOCIETY OF ONTARIO  
PRESENTATION TO THE STANDING COMMITTEE  
ON FINANCE AND ECONOMIC AFFAIRS**



**February 01, 2010**

**Alzheimer Society**  
ONTARIO

## **INTRODUCTION**

Mr. Chair, Members of the Committee, Ladies and Gentlemen

Thank you for providing the Alzheimer Society of Ontario the opportunity to present to you on the issues related to dementia in Ontario. We appreciate that last week you heard from the Northern Alzheimer Society chapters.

As well, in December 2009, we presented to Minister Duncan during his pre-budget consultation sessions, on the issues related to care giving.

Minister Duncan responded that:

1. He is obligated to look at the issue of care giving;
2. The rising rates of dementia are precisely the problem in terms of rising health care costs;
3. He agreed that we need to keep people at home and understands that to do this people need to be supported;
4. The focus needs to be on leveraging existing programs and strategizing for long-term solutions;
5. He asked that the Alzheimer Society of Ontario demonstrate the costs of care giving and how any proposed interventions would curb spending.

Today our presentation builds on Minister Duncan's recommendations to leverage existing programs, outline the costs of care giving and how our proposed interventions will curb future spending in Ontario.

Also, in the November 29, 2007, Speech from the Throne, this Government made a commitment to provide caregiver grants to those caring for elderly family members. In 2010, we have yet to see this commitment fulfilled. This submission will demonstrate the increasing need for this and other supports for caregivers in Ontario.

### **About the Alzheimer Society**

The Alzheimer Society of Ontario, founded in 1983, supports a province-wide network of 39 chapters to:

- Improve service and care,
- Fund and advance research,
- Educate the communities it serves,
- Create awareness and mobilize support for the disease.

Our Society's vision is a world without Alzheimer's disease and related dementias. We are affiliated with the Alzheimer Society of Canada and with Alzheimer Disease International. In spring 2011, the Alzheimer Society will proudly welcome people from 71 countries to the 26th Alzheimer Disease International conference in Toronto.

Alzheimer Society chapters provide a range of services including group supports, counselling, information, public awareness and dementia specific education for front-line health service providers, those diagnosed with the disease and their families and caregivers. Some chapters also provide day programs and longer-term respite care.

The Alzheimer Society of Ontario and the chapters work in partnership with health service providers, primary care practitioners, long-term care facilities, and clients. We have a long history of working together to improve access to services for clients, promote best practices in dementia care and raise the profile of dementia-related issues.

In Ontario, 26 Alzheimer Society chapters offer the First Link program that provides recently diagnosed individuals and their caregivers with comprehensive and coordinated services by reaching out as early as possible in the disease process. First Link collaborates with the diagnosing primary care physician, other members of the primary care team, diagnostic and treatment services, community service providers, and the Alzheimer Society.

In addition, the Alzheimer Society of Ontario is a leading member in the Ontario Caregiver Coalition. This coalition is dedicated to bringing issues related to family care giving to the policy table.

Family caregivers care for spouses, children, parents and other extended family members in need of support due to age, debilitating medical conditions, chronic injury, long term illness or disability. Family caregivers are the foundation of Ontario's health care system, yet they are largely invisible. They are overlooked by health service providers and seldom acknowledged in public policy.

## **PRESENTATION**

The focus of our presentation is on the following;

- Prevalence and Impact of dementia
- Critical needs for moving forward to better support people living with dementia and their caregivers and at the same time to curb the increasing health care spending in Ontario
- Ontario's leadership in championing national solutions

### **What is dementia?**

Dementia is a large class of disorders characterized by the progressive deterioration of thinking ability and memory including eventual loss of memory, judgment and reasoning and changes in mood, behaviour and communication abilities.

These symptoms may affect a person's ability to function at work, in social relationships or in activities of daily living.

Alzheimer's disease, the most common form of dementia, is a progressive, degenerative disease of the brain, which causes thinking and memory to become seriously impaired. After Alzheimer's disease, Vascular Dementia (VaD) is the second leading cause of dementia.

## **PREVALENCE AND IMPACT OF DEMENTIA**

More than 180,000 people in Ontario have dementia and in less than 25 years, the number will double.

Dementia is the leading cause of disability in Ontarians over 60, causing more years lived with disability than stroke, cardiovascular disease and all forms of cancer.

Most Ontarians with dementia today are supported outside of institutions, in their homes with their families.

Studies have shown that caregivers are under considerable psychological, physical and financial stress (despite enjoying the inherent satisfaction of caring for their loved ones). Caregivers of people with dementia report stress levels 3 times greater than those caring for persons with other chronic diseases, and depression is nearly twice as common (Alzheimer Society of Ontario, 2007).

In 2008, informal caregivers of people with dementia in Canada provided 231 million hours of care. By 2038, that will increase to 756 million hours (Alzheimer Society of Canada, 2010).

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. Caregivers provide more than 80% of the care needed by individuals with long-term health conditions (Fast, Eales and Keating, 2001).

In Canada, the economic burdens of dementia will double every decade, increasing from \$15 billion in 2008 to \$153 billion in 2038 (Alzheimer Society of Canada, 2010).

In partnership with the Ontario Government we have the opportunity to curb this spending to ensure that investments are effective and multi-purposed.

## **WHAT IS NEEDED?**

Today, we will highlight two key areas of support needed by caregivers. The first is increased access to respite care and support of the First Link program. The second is financial support.

***Respite care***

Respite services offer temporary relief from care giving. They include: (1) in-home respite where an alternate (usually paid) caregiver comes to the home for a few hours; (2) adult day programs where the person with dementia is taken to a community centre for a specified number of days in the week; (3) or, overnight respite, which is usually in short-term beds of a long-term care home or in purpose-built respite homes, of which there are only 3 in Ontario. These are owned and/or supported by local Alzheimer Societies.

There are 4 key issues with respite in Ontario:

1. Caregivers are unaware of available services or often act too late
2. There is an insufficient supply of respite, especially short-term.
3. The services that are offered do not fit with family needs (i.e. hours, continuity of staff).
4. The cost of in-home respite is too high for already strained caregivers.

These 4 key issues must be dealt with by future investment from the Government; however as Minister Duncan advised in December, we need to leverage existing programs.

Many caregivers are not receiving the support they need because they are not aware of the services available to them. As described earlier, the First Link program links persons with dementia and their caregivers to community services from the time of diagnosis. Through First Link caregivers can maximize existing programs.

Although it has been proven effective, First Link is only supported by 57% of Local Health Integration Networks (LHINs). The First Link program must be sustained in the 26 communities currently offering the program, and expanded to all communities across Ontario.

***Financial support***

In a study of family caregiver needs, it was found that financial issues are a major concern (Dupuis & Smale, 2004), for 2 major reasons:

- Caregivers who are in the workforce and choose to care for their relative give up salary, career and pension prospects for many years or retire early.
- Additional expenses related to providing care for a person with dementia include, fees for home care services, transportation costs for medical appointments, drug dispensing fees, technical aids and equipment, and home modification.

According to caregivers the financial strains of caring for a person with dementia and providing adequate financial compensation for their work was critical.

Caregivers asked for:

- Caregiver compensation such as caregiver tax credits, subsidies to pay for equipment, medications and other needed caregiving supplies, direct payment for care, and accommodation/travel grants if they have to travel to receive care;
- affordable services regarding the cost of care, particularly services/programs;
- self-directed funding options; and,
- caregiver job, pension and benefit protection, as well as adequate caregiver leave policies.

(Dupuis & Smale, 2004).

Providing financial support to caregivers is not without precedent. Australia offers a Carers Allowance and a Carer Payment. The United Kingdom and Nova Scotia also have similar payments available to caregivers. Coupled with enhanced tax credits, caregiver allowances would provide strong support for caregivers

We also call on government to champion caregiver supports in federal, provincial, and territorial discussions just as Ontario is a major force in pension reform. More options in Compassionate Care Allowance and

dropout provisions for caregivers, similar to the Canada Pension Plan provisions for family child rearing, are needed.

**SUMMARY OF REQUESTS:**

- **Ontario develops a comprehensive strategy for dementia and Alzheimer's Disease.**
- **Expand the First Link program in order to maximize to existing services.**
- **Invest in financial supports for family caregivers.**
- **Provide leadership to the federal government on caregiver policy.**

By continuing to leverage existing programs and committing to new investments for caregivers we have the opportunity to curb increasing health care spending.

Thank you.

## REFERENCES

Alzheimer Society of Canada (2010). *Rising Tide: The Impact of Dementia on Canadian Society*.

Alzheimer Society of Ontario (2007). *A Profile of Ontario's Home Care Clients with Alzheimer's Disease or Other Dementias*.

Dupuis & Smale (2004). *In Their Own Voices: Dementia Caregivers Identify the Issues. Stage 2: The Focus Groups*. Murray Alzheimer Research and Education Program, University of Waterloo.

Fast, Eales & Keating (2001). *Economic Impact of Health, Income Security and Labour Policies on Informal Caregivers of Frail Seniors*. Ottawa: Status of Women Canada.

**Alzheimer Society**  
ONTARIO

20 Eglinton Avenue West, Suite 1600, Toronto ON M4R 1K8  
Tel. 416-967-5900 • Fax 416-967-3826 • [www.alzheimerontario.org](http://www.alzheimerontario.org)