

Alzheimer Society of Ontario  
Submission on Bill 173, the Budget Measures Act 2011  
to the  
Standing Committee on Finance and Economic Affairs  
April 21, 2011

**Introduction**

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

Thank you for giving the Alzheimer Society of Ontario (ASO) the opportunity to present to the Select Committee on Finance and Economic Affairs on the issues related to dementia as connected to the 2011 Ontario budget.

***What is dementia?***

Dementia is a large class of disorders characterized by the progressive deterioration of memory, judgment and reasoning and can lead to 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**

Today, more than 181,000 people in Ontario have dementia. In 10 short years, this number is expected to increase 40%, to 255,000 people. 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 (Alzheimer Society of Ontario, 2010).

The annual total economic burden of dementia in Ontario is expected to increase from \$7.1 billion in 2010 to \$19 billion in 2020. This number includes the direct costs of health care services, the opportunity costs of caregiving's impact on the ability to work, and the indirect costs of lost productivity and lost wages (Alzheimer Society of Canada, 2010).

Direct costs of dementia to the health system are projected to increase by \$440 million each year through 2020 (Alzheimer Society of Canada, 2010). In partnership with the Ontario government, we have the opportunity to curtail these costs to ensure that investments are effective and multi-purposed.

## ***About the Alzheimer Society***

The Alzheimer Society of Ontario, founded in 1983, supports a province-wide network of 38 local Societies 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 other dementias. We are affiliated with the Alzheimer Society of Canada and with Alzheimer Disease International. Local Alzheimer Societies offer 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 Societies, like ours in Windsor Essex, also provide day programs and longer-term respite care.

The Alzheimer Society of Ontario and the local Societies 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.

The Alzheimer Society of Ontario is a founding and leading member of the Ontario Caregiver Coalition. This coalition of caregivers, health charities, and community and health service providers is dedicated to bringing issues related to family caregiving to the policy table. *Family caregivers* care for spouses, children, parents and other extended family members who need 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 sometimes overlooked by health service providers and seldom acknowledged in public policy.

## Presentation

A close examination of alternate level of care beds in Ontario shows dementia accounts for 25% of alternative level of care hospitalizations and 34% of alternative level of care days (CIHI, 2009). In addition, over 70% of long-term care residents have some form of dementia (OHQC, 2010).

The Alzheimer Society of Ontario applauds the government for increasing funding to the community services sector by three percent annually over the next three years. This increase in funding is what is needed to coordinate services for people living with dementia and their caregivers in the community and in long-term care. With funds established for the next three years, the focus must now be on implementing a comprehensive plan that will address the needs of people living in the community and long-term care and enhance health system performance. As you may already be aware, the Alzheimer Society of Ontario has developed an action plan to help people living with dementia and their caregivers. *10by20: Ontario Action Plan for Dementia* focuses on brain health, early intervention, caregiver support, strengthening skills in dementia care across the workforce, and investing in research and the dissemination of findings into practice. The implementation of this plan is now possible using a portion of the indicated three percent per annum investment in the community service sector.

### **First Link<sup>®</sup>**

One program that could benefit from this investment is the First Link<sup>®</sup> program. It 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 enables collaboration between the diagnosing primary care physician, other members of the primary care team, diagnostic and treatment services, community service providers, and the Alzheimer Society.

Many caregivers are not receiving the support they need because they are not aware of the services available to them. Through First Link, primary care providers refer those who are newly diagnosed to their local Alzheimer Society to ensure that caregivers maximize their awareness of existing programs.

Even though evaluation of the demonstration projects shows that the program is effective, First Link<sup>®</sup> is only available to 73% of Ontarians, as York Region, Kingston, North Bay, Lanark County, Leeds-Grenville, Sudbury, Toronto, Bellville-Hastings, and Prince Edward County continue to face challenges in securing adequate funding. To ensure all Ontarians diagnosed with dementia receive the education, information and access to services they need, the First Link<sup>®</sup> program must be expanded to all communities across Ontario.

An initial investment of approximately \$1.5 million to expand First Link to the remaining nine regions, and an ongoing investment of \$400,000 each year to sustain the program are needed to provide this service to all Ontarians. This represents a relatively small portion of the total new investment in the community services sector outlined in the budget.

### Alzheimer Society of Ontario

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## **Flexible Respite**

Respite services offer temporary relief from caregiving, but there are four key issues with respite in Ontario:

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

Still, innovative respite options exist in some regions of Ontario. They include the Seniors Managing Independent Living Easily program, or SMILE, in the South East, Wesway in the North West, and the Veterans Independence Program through Veterans Affairs Canada. By tailoring services to meet their needs, these flexible respite programs enable caregivers to support the person with dementia more effectively and extend independent living for the person with dementia. Most importantly, it keeps people in their homes with those who love them.

With a modest investment to expand these existing programs, the Ontario government could reduce the amount spent on institutional care by prolonging the time people with dementia can remain at home.

## **Health Promotion/Prevention**

Ontario's commitment to health promotion and illness prevention has been demonstrated through the Ontario Diabetes Strategy, a great first step in reducing costs to the health system by helping people prevent Diabetes and manage their current illness. We commend the government on making health promotion and illness prevention a priority and encourage you take this approach to increase awareness of the ever increasing numbers of people being diagnosed with dementia.

Prevention is possible, but people need to know what to do and how to do it. They also need help in managing the social and socioeconomic changes that occur once progression of the disease is underway. A marketing campaign to promote prevention, brain healthy lifestyles and self-management of dementia through information about healthy living and warning signs would reach more Ontarians and increase awareness of the disease and reduce misconceptions.

## **Primary Care**

The Ontario government has shown commitment to improving access to primary care services for all Ontarians. Access to primary care increases early identification of illness and intervention. The government has already created 200 Family Health Teams across Ontario. They have the capacity to enhance the care received by those in the early stages of dementia who are looking for a diagnosis and intervention options.

An Ontario model of training Family Health Teams to conduct Memory Clinics has proven effective in increasing the capacity of primary care, providing early diagnosis, and

comprehensive management of the disease. Developed in Kitchener, thirteen teams are currently serving a client base of 300,000. This approach can be scaled to reach all teams across Ontario. People will be diagnosed earlier and better use will be made of scarce specialist resources. An investment of \$480,000 each year will expand the training of Family Health Teams in the memory clinic model. The time commitment of Family Health Teams to Memory Clinics is minimal, but the potential impact is great for those who are struggling with dementia symptoms and their families.

### **Mental Health**

We are pleased to see that the Ontario government has shown commitment to investing in a comprehensive Mental Health and Addictions Strategy. While we understand that this strategy will begin with a focus on children and youth, the roll out of the full plan must encompass the mental health and addictions needs of seniors. As the fastest growing population in our province they have the potential to place tremendous strain on the system if we are not prepared.

Effectively responding to the needs of seniors should always include a focus on dementia prevalence and its relationship to mental health. A diagnosis of dementia can be challenging for a person to cope with, and both the person with dementia and their caregiver can experience anxiety or depression throughout the course of the disease.

In addition, people with dementia often display what we call “responsive behaviours”, such as physical resistance or wandering. These behaviours may be due to a variety of reasons, including discomfort in physical surroundings or inability to communicate thoughts and feelings. Currently no coordinated effort is in place for health service providers to respond to the challenges these behaviours present.

In 2010, the Alzheimer Society of Ontario partnered with the Ministry of Health and Long-Term Care to develop a support system to address responsive behaviours in care settings. The Ontario Behavioural Support Systems Project aims to improve the lives of Ontarians with behaviours associated with complex and challenging mental health, dementia or other neurological conditions living in long-term care homes or in independent living settings. This approach should to be expanded to help those receiving care services in their own homes in the community to provide a system wide approach to behavioural health.

### **Summary**

Services available to people living with dementia and their caregivers need to be coordinated through a comprehensive plan to maximize the investment outlined in the 2011 Ontario budget. The projected increase in dementia prevalence of 40% by 2020 means we must respond to the needs of this population today in order to be prepared for tomorrow.

With investment in the community services and mental health sectors Ontario has the opportunity to implement a comprehensive plan of care to address access to flexible respite, primary care, and mental health needs while increasing awareness of dementia, promoting prevention and ensuring people have access to service information through the expansion of First Link®.

Thank you

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