

Presentation to the Select Committee on Mental Health and Addictions



June 16, 2009

Introduction

We are privileged to speak with you on behalf of Ontarians affected by dementia today and in the future. Our message to you is simple:

- The demographics of dementia can overwhelm the health system unless we are prepared.
- The essentials for preparedness are already in place.
- A comprehensive response involves all of us and in particular the mental health sector.

About the Alzheimer Society

The Alzheimer Society of Ontario (ASO), 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 (ADRD). 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, counseling, information, public awareness and dementia specific education for front-line health service providers. Some also provide day programs and respite.

ASO and the chapters work in partnership with a variety of groups, including health service providers, primary care practitioners, 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.

What is dementia?

Dementia is a syndrome with symptoms that include 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 day-to-day activities.

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 impaired¹.

After Alzheimer's disease, Vasular Dementia (VaD) is the second leading cause of dementia.

Prevalence and Impact

More than 180,000 people in Ontario have dementia and in less than 25 years, the number will double².

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 cancer³.

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

Care partners 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 common⁴.

Dementia has a dramatic impact on the health system as well. Persons with dementia use one third of Alternate Level of Care bed-days. Dementia is highly correlated with hip fractures and persons with dementia occupy over 60% of our long-term homes⁵. 57% of older persons presenting at one emergency room had a cognitive impairment.

Today, there is no cure. Dementia is fatal.

¹ Alzheimer Society of Canada (2009). *What is Alzheimer's Disease?* Retrieved from: <http://www.alzheimer.ca/english/disease/whatisit-intro.htm>

² *Rising Tide – The Impact of Dementia on Canadian Society*. Alzheimer Society of Canada

³ World Health Organization (2007). *Global Burden of Disease estimates*, as reported in Dementia UK

⁴ Alzheimer Society of Ontario (2007). *A Profile of Ontario's Home Care Clients with Alzheimer's Disease or Other Dementias*.

⁵ Alzheimer Society of Ontario (2007). *It's Time to Act, Ontario's Dementia Imperative*.

The Dementia/Mental Health Interface

Progress in dementia care is tied to progress in mental health, especially in addressing stigma, advancing health promotion, strengthening primary care and expanding specialized mental health services.

Stigma

A 2006 nationwide public opinion poll revealed that Alzheimer's disease is the second most feared disease by Canadians, preceded only by Cancer. This fear is rooted in the misconceptions and stigma surrounding dementia.

Persons with dementia face double stigmas, one associated with mental illness, the other associated with ageism.

Often older people feel excluded, diminished and marginal because of our fast-paced, youth exploitive society. Add to this, the experience of gradual cognitive decline and the accompanying self-doubt and you have a potion that inhibits self-disclosure and leads to isolation. Our health service response often reinforces these feelings.

Prevention

A common misconception is that dementia is inevitable as we age. The truth is that not every old person develops dementia. While age is the most significant risk factor, researchers think that the disease process starts years before symptoms appear.

A healthy lifestyle including healthy eating, taking part in regular physical activity, and participating in activities that involve socializing and stimulating brain activity all reduce risk for developing dementia.

Primary Care

The strengthening of primary care is the key. A primary care practitioner skilled in the ability to identify, diagnose and treat mental illness, in a collaborative style, possesses the same skills, knowledge and attitude that will benefit a person with dementia.

Differential diagnosis is central to dementia identification, as depression and delirium among other conditions, can appear as dementia. The type of dementia also drives treatment responses. As well, in a family practice setting, the health of the care partner is monitored as closely as that of the person with dementia.

Specialized Geriatric Mental Health

A multi-skilled, flexible primary care service working in collaboration with specialized geriatric mental health offers a 'powerful' team approach to supporting persons with dementia. In the later stages of dementia, responsive behaviours may emerge that can cause harm to the person or others. Specialized Geriatric Mental Health services provide added expertise in diagnosis, behavioural strategies and pharmacological treatment. As well, pre-existing serious mental illness can present exceptional challenges when combined with dementia, in an older person.

Dementia Specific Supports

As mentioned, Alzheimer Society chapters offer a range of support services for people with dementia and their care partners including counseling and support groups.

Counseling

Counseling offers people with dementia and their care partners the opportunity to understand and cope with dementia, plan for the future, discuss needs and issues, and learn about other community resources.

Support Groups

Support groups offer an opportunity for people with dementia and their care partners to meet, learn and share with others that are going through similar experiences.

These critically important support services for people with dementia and their care partners should be included in your recommendations. These services are needed in the community throughout the continuum of the condition.

Policy

Until persons with dementia are unequivocally identified as people who may benefit from the involvement of mental health practitioners, the struggle for adequate and well-planned supports for persons with dementia will continue.

Policy workers in government and planners in the Local Health Integration Networks are cognizant of the issues, but must wrestle with a history of indecisive policies that confuse all concerned. Initiatives to redesign mental health often overlook the potential partnerships possible in an enriched long-term care system and strategies to promote aging at home are inhibited by debates around this issue.

Solutions and Strategies

Along with our case for integration of dementia into mental health, Mr. Chair and Members, we also wish to outline some solutions and strategies that the Alzheimer Society are undertaking to eradicate stigma and engage in coordinated health promotion activities

Fostering Supportive Communities

Each Ontario chapter has a provincially funded Public Education Coordinator who works in disseminating education about dementia across the broad community and with health practitioner. We are increasing our outreach to persons with developmental disabilities and Aboriginal people.

As well, we are working in partnership with the Murray Alzheimer Research and Education Program, at the University of Waterloo, to finalize an approach to Age-Friendly Communities that will help communities become more supportive of all persons with impairment, but especially persons with cognitive impairment. We recognize that 'it takes a whole village to support a vulnerable person'.

Dr. James Orbinski, a Canadian physician, writer, humanitarian and activist has been quoted as stating "stigma ends when there are solutions to the issues". Our solutions are centred on awareness, understanding, education and partnership.

Prevention

The risk reduction activities that are identified for dementia are the same for many other chronic diseases, such as heart disease and diabetes. For this reason, ASO became a partner organization with the Ontario Chronic Disease Prevention Alliance (OCDPA) whose mission is to provide leadership for a comprehensive chronic disease prevention system for Ontario. The OCDPA sponsored a think tank on mental health and health promotion.

Emerging Opportunities for Support Services

First Link

In 2002, the Champlain Dementia Network piloted a First Link project that reached out to persons with dementia and their families by obtaining a referral from the diagnosing clinic and directly contacting people to offer information and support.

During 2007-09, we expanded the pilot to a nine-site Demonstration Project. Since, we have expanded to 25 sites with the support of 8 LHINs. So far, much of the GTA remains unserved by First Link but we hope that this initiative will be supported in year 3 of the Aging at Home Strategy.

First Link offers primary care practitioners the assurance that their efforts will be augmented by community agencies skilled in this area. Their patients will be provided with education, self-management tools and will have on-going contact.

Behavioural Support Services

Ontario is on the verge of a new level of support for older persons with responsive behaviours. In April, more than 70 persons involved in serving, supporting or planning for this population met with Ministry staff to explore how innovation could drive improved services. For decades, Ontario has struggled to evolve a service model for this group of vulnerable older people. Sadly, the Casa Verde Inquest in 2005 showed us that we have much further to go.

Recommendations that you make to strengthen community care should address this area of need, in particular.

Call to Action

Your committee has an important role in urging our government, health providers and communities to action. We ask you to include in your call to action, the following:

1. That Ontario's Mental Health Policy and Service Framework include the needs of persons with dementia and their care partners, especially at the stages of diagnosis and early intervention, and when responsive behaviours may emerge.
2. That efforts to address stigma encompass dementia and ageism.
3. That service capacity keeps pace with the growing numbers of persons with dementia and care partners throughout the continuum of the condition.

Mr. Chair and Members, we need to work together to address dementia consistent with our social values and traditions. The impact of dementia is immense and will increase. If unprepared, we are at-risk of being overwhelmed. If prepared, we are confident that our communities will be able to cope and Ontarians with dementia will live with dignity and care partners will be supported.

References

Alzheimer Society of Canada (2009). What is Alzheimer's Disease? Retrieved from: <http://www.alzheimer.ca/english/disease/whatisit-intro.htm>

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