

Caring for the Caregivers

**Alzheimer Society of Ontario's
Response to the 2008 Pre-Budget Consultations**



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Alzheimer Society
ONTARIO

On the cover:

Retired high school teacher and author, Douglas Kearn, and caregiver Arlene Kearn at The Beach neighbourhood in eastern Toronto. Douglas has been diagnosed with mild cognitive impairment that his doctors say may eventually develop into Alzheimer's disease.

No one should face dementia alone.

Introduction

The Alzheimer Society of Ontario welcomes the government's concern for Ontario's seniors and supports initiatives such as the Aging at Home Strategy and steps to improve long-term care homes.

In the November 29, 2007 Speech from the Throne, the Government made a commitment to seniors who want to stay in their own homes by broadening the services available to seniors in home care and by providing caregiver grants to those caring of elderly family members. The Alzheimer Society welcomes this initiative, urges quick action, and offers our strong support and commitment to work with you in making this promise a reality.

An aging population and its health challenges

It is well known that Ontario's population is aging. In the next ten years there will be about half a million more seniors in Ontario than there are now.ⁱ Over the same period the number of seniors with Alzheimer's disease and related dementiasⁱⁱ will increase by about 46,500, rising from 170,000 in 2008 to 207,000 in 2016. This is just seniors; the number does not include people who have early onset dementia before they are 65, which some estimate could be an additional 10 per cent.

As our bodies and minds age, the risk of developing a serious illness or disability increases. For example:

- 15.5% of Ontarians have at least one disability. This disability rate increases with age so that by 65 one in three Canadians has a mobility-related disability, rising to 45% among those over 75.ⁱⁱⁱ
- Age is the biggest risk factor for dementia— about 90% of people with dementia are over 65. While in general dementia affects almost 10% of all seniors over 65, the rate increases with age from 2% of Ontarians aged 65-74, 12% of those between 75 and 85, and 40% of those over 85.
- Co-morbidities exacerbate this situation even further, especially with dementia. The rate of co-morbid conditions among persons with ADRD served by Community Care Access Centres is 20% higher than other long stay clients, with each person having an average of 3.9 other diagnoses.^{iv}

As the number of seniors with their concomitant frailties increases, the demand for caregivers, community services and healthcare services to support them will also increase. This is a wide-ranging issue not confined to people with dementia but one where dementia may serve as a significant indicator of how well we, as a society, look after and respect our valued seniors.

Across Ontario, caregivers contribute to the economic health of our province in real and significant ways. The unpaid care and support they provide to family members, neighbours and friends results in fewer seniors requiring costly, publicly funded long-term care or emergency hospital services. Though the economic contribution of unpaid caregivers is not tallied, it is no

less significant. Without the contribution of Ontario's unpaid caregivers, our health care system would undoubtedly collapse. With Ontario's aging population and the increasing strain on our health care system and community support services, the importance of supporting caregivers has never been so great or so urgent.

What is the problem?

As recognized by the Aging at Home Strategy, many of the seniors who have health-related concerns prefer to remain at home with support rather than be in a hospital or long-term care home. Over half the people diagnosed with dementia live at home in their community. Not only is aging at home the preference of many Ontarians, if adequately supported, it can also be cost-effective as it delays the use of more expensive care.

To remain at home in the face of physical and/or mental frailty requires not only community support but also frequently a live-in caregiver. For people with dementia, this caregiver is usually a family member — typically a spouse or adult child — and usually female. It's worth remembering that many are seniors themselves with their own health concerns.

The problem is one of caregiver pressure. Caregivers are a shadow workforce — untrained, undersupported, unseen, unpaid. They act as geriatric case managers, medical record keepers, paramedics, homemakers and family advocates. People with dementia can be demanding; they may exhibit impairment of short-term memory and cognitive skills required for daily decision-making, difficult behaviours and high rates of mood disturbance. Caregivers of people with dementia are required to give "extraordinary care" that may require the performance of tasks that are physically demanding, unpleasant, and disruptive of other social and family activities. The stress levels reported by caregivers for people with AD/DRD is 200 per cent greater than for caregivers of persons with other significant needs.^v

Caregivers are also hidden patients and are at risk for social isolation, stress, depression and mortality. While there is inherent satisfaction in looking after a family member, caregivers' health can be compromised when they are overloaded with more responsibilities than they can manage, required to perform tasks that are emotionally difficult, or if they feel trapped by the demands of care. They have little time to renew themselves or to take care of their own health concerns. And looking after someone with dementia can last a long time (a person with dementia may live up to ten years from time of diagnosis to end of life). Depression is nearly twice as common in people caring for someone with dementia as in other caregivers.^{vi}

Financial worries are an added source of strain for caregivers. Many caregivers are seniors, perhaps on fixed income, and tight finances mean that they are unable to purchase needed supports such as home care or respite care. Caregivers who are in the workforce and choose to care for their relative give up their salary and career and pension prospects for many years or retire early — which results not only in financial difficulties for the caregiver but also lost productivity for the economy.

The danger is that, without adequate support, caregivers will no longer be able to cope. They will become patients themselves and their relatives may be placed prematurely in a long-term care home. Lack of adequate support creates more family stress and greater pressure on the health care system. And the problem will be exacerbated by the aging population.

What supports do caregivers need?

Caregivers have asked for respect and recognition of the role that they play, for education and training to help them manage their caregiving tasks, counselling and support to help alleviate the emotional stresses, respite care and financial support.^{vii} Here, we focus on the last two needs.

Respite care

Respite services offer a temporary break from caregiving and are one of the most requested services. Three main types of respite are: (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.

Despite caregivers' expressed desire for adequate respite, there remains a gap between what is offered and what is needed. There are several reasons. First, is an insufficient supply of respite, especially short-term, in-home respite. Where respite is available, we have found that the number of hours of help is still inadequate.

The second is that services offered are a poor fit with the family's needs. The hours offered by the agency do not match the family's needs (e.g. mornings only when a medical appointment is in the afternoon) or there may not be enough hours in a single block of time to be useful. The family may be uncomfortable having strangers in their home, and with high turnover and little continuity in staff or lack of training in caring for someone with dementia, there may be little opportunity to develop a more effective relationship.

A third is the cost. Our member chapters indicate that in-home respite costs about \$25-30 per hour. The recent pressures on Community Care Access Centres to respond to the wait times strategies has lessened respite once available through them. Services purchased privately are high cost. In a survey of dementia caregivers in Ontario, one third of respondents said that community support services were too expensive.^{viii}

What would be most effective is a menu of flexible options and self-directed funding that enables families to choose the respite care that best meets their needs.

Financial support

In a study on caregiver needs^{ix}, financial issues were a major concern. Caregivers stressed that recognizing the financial strains of caring for a person with dementia and providing adequate financial compensation for their work was critical to valuing the caregiving role^x. They 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.

Providing financial support to caregivers is not without precedent. Australia offers a Carers Allowance and a Carer Payment.^{xi} About 58 per cent of all primary caregivers receive either the Carer Allowance or the Carer Payment.^{xii}

- Carer Allowance is a supplementary payment for caregivers who provide daily care and attention for an adult with a disability, severe medical condition or who is frail aged at home. The Carer Allowance may be paid on top of Carer Payment or other payments, such as state pension. The Carer Allowance is not means-tested and is currently \$100AUD every two weeks (about \$88CAD).
- Carer Payment is an income support payment for people who are unable to support themselves through participation in the workforce while caring for someone with a disability, severe medical condition or who is frail aged. It is means-tested and currently provides \$537AUD (\$476CAD) every two weeks for a single person, \$499AUD (\$442CAD) each for a couple.

What is available now?

There is some financial assistance available today, often focused on the person with the disability, e.g., financial support for physical modification to their home.

Caregivers may be eligible for a tax credit for in-home care of a relative (maximum claim of \$4,031 reduced by dependant's net income in excess of \$13,792)^{xiii}, or for Employment Insurance compassionate care leave benefits.

However, the existing supports have limitations. For example, tax credits are only useful if you have enough income to apply it against, and they are delayed, i.e. do not help with paying for respite care today. Compassionate care leave benefits are helpful but, for caregivers of people with dementia, these benefits are short-term and many seniors would be ineligible for this type of Employment Insurance benefit.

We are aware of Ontario models such as the Special Services at Home program for families with children with high needs and the self-directed program for individuals with needs for attendant services. Such grants are specifically targeted to the caregiver enable them to choose the type of support that is most effective at the right time for their individual circumstances. The dementia journey involves continuous change and adaptation, so flexible support is key.

We urge you to consider age as a factor for eligibility. As many as 10 per cent of persons with dementia are under 65 at the time of diagnosis. Often, these people and their families experience challenges with elder-oriented service providers. They may have younger families, working spouses and different social needs. Opportunities for customized support packages are most needed here.

The benefits of caregiver grants

Taking a preventative rather than crisis approach to caregiver support yields many benefits.

Caregiver grants empower caregivers and enable them to manage care for both themselves and the person needing care. Meeting caregiver needs for support helps the caregiver to remain mentally and physically healthy, gives them time to attend training and support sessions (as well as enabling the person with dementia to have added stimulation), provides the preferred care to the person with dementia, and delays placement in more expensive care.



There is evidence that caregivers who use respite services and other supports such as education and counselling maintain their relatives in the community longer than caregivers who do not use those services. In one study, use of counselling and support programs could delay placement by up to 1.5 years.^{xiv} Caregiver grants greatly enhance the ability of caregivers to access these services and thereby improve their ability to cope and lengthen the time their family member remains at home.

Our recommendations

The Alzheimer Society of Ontario has two requests:

- We recommend that the government implement caregiver grants to those caring for family members as soon as possible.
- We would like to be included in consultations for developing the details of the caregiver grant program.

Thank you for your consideration. We look forward to hearing from you.



APPENDIX

The people

There are 170,000 people in Ontario with Alzheimer's disease or related dementias, almost all of them seniors. Since age is the primary risk factor, this number is expected to spike in the next five years as the baby-boomers become seniors.

Over half of people with dementia live at home in their community. Most of them have a primary caregiver who is either a spouse — and probably also a senior with his or her own aging challenges — or an adult child (usually a daughter) who may also have job and/or child responsibilities.

Alzheimer's disease is a progressively degenerative disease whose progress can last up to ten years or more. As the disease progresses, people with dementia are typically affected by:

- increasing functional loss of their ability to perform the activities of daily living, both personal activities such as bathing, dressing or personal hygiene, and instrumental activities such as preparing meals, managing medication or attending to finances;
- declining short-term memory and the cognitive skills needed for daily decision-making; and,
- for some, the development of responsive behaviours, such as wandering, being verbally or physically abusive or resisting care, and/or mood disruptions such as persistent anger or unrealistic fears.

People with dementia become increasingly less able to manage for themselves and ultimately are totally dependent on others.

The numbers

Dementia Projections in Ontario^{xv}

LHIN	Region	2006	2016
	Ontario	155,571	207,188
1	Erie St. Clair	8,623	10,593
2	South West	13,600	16,805
3	Waterloo Wellington	7,930	10,942
4	Hamilton Niagara Haldimand Brant	20,452	25,821
5	Central West	5,991	9,395
6	Mississauga Halton	9,426	14,788
7	Toronto Central	15,471	18,708
8	Central	16,883	24,905
9	Central East	18,837	25,269
10	South East	7,470	9,230
11	Champlain	14,629	19,215
12	North Simcoe Muskoka	5,552	8,175
13	North East	7,697	9,840
14	North West	3,010	3,501

The organization

The Alzheimer Society of Ontario, founded in 1983, supports a provincial 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. The Society's vision is a world without Alzheimer's disease and related disorders.

ⁱ Based on data in Ontario Ministry of Finance. (2008). *Demographic Quarterly: Highlights of the Third Quarter 2007*. Over 65s in 2007: 1.7 million (12.804 million x 13.2%). Over 65s in 2016: 2.2 million in 2016 (14.248 million x 15.4%).

ⁱⁱ All references to dementia imply Alzheimer's disease and related dementias.

ⁱⁱⁱ Statistics Canada, *Participation and Activity Limitation Survey 2006*, accessed from <http://www.statcan.ca/english/freepub/89-628-XIE/2007002/profileadults-en.htm#a5>

^{iv} Alzheimer Society of Ontario (2007). *A Profile of Ontario's Home Care Clients with Alzheimer's Disease or Toher Dementias: Drawn from RAI-HC Assessments, 2005*

^v Ibid.

^{vi} Canadian Study on Health and Aging Working Group: *Patterns of caring for people with dementia in Canada*. Canadian Journal of Aging 1994, Vol. 13 no. 4:470-487.

^{vii} See, for example, Smale, B. & Dupuis, S.L. (2004). *In Their Own Voices: A Profile of Dementia Caregivers in Ontario*. Stage 1: Survey Results. Murray Alzheimer Research and Education Program, University of Waterloo.

^{viii} Smale & Dupuis, p. 31.

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

^x Ibid.

^{xi} Australia, Centrelink (an Australian government agency). Accessed from

http://www.centrelink.gov.au/internet/internet.nsf/payments/carer_allow_adult.htm

^{xii} Sharlach, A. (2002). *Aged and family care in Australia*. Berkeley CA: University of California, Berkeley, School of Social Welfare, Center for Advanced Study of Aging Services. Cited in Montgomery A. & Friss Feinberg, L. (2003). *The Road to Recognition: International Review of Public Policies to Support Family and Informal Caregiving*. Policy Brief. Family Caregiver Alliance.

^{xiii} Ontario Ministry of Finance. (2007). *Ontario Outlook and Fiscal Review*, Annex V: Transparency in Taxation, Table 2.

^{xiv} Mittleman, M.S., Haley, W.E., Clay, O.J. & Roth, D.L. (2006). Improving caregiver well-being delays nursing home placement of patients with Alzheimer disease. *Neurology* 67: 1592-1599.

^{xv} Alzheimer Society of Ontario. (2007). *Projected Prevalence of Dementia: Ontario Local Health Integration Networks*



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