

Public Policy

Shaping The Future:

*Help for Today and Hope for Tomorrow
for People Affected by Alzheimer Disease
and Related Dementias*

Prepared by The Alzheimer Society of Ontario
January 2003

*A Vision for Public Policy That Will Provide
Help for Today and Hope for Tomorrow
for
People Affected by Alzheimer Disease and Related Dementias*

1. APPROPRIATE SERVICES THROUGHOUT THE DISEASE PROCESS

Individuals affected by Alzheimer Disease and related dementias and their caregivers will have access to appropriate services throughout the disease process.

- Province-wide access to appropriate services and improved service co-ordination, integration and sustainability.
- Environments that support quality of life.
- Access to knowledgeable staff.
- Access to knowledgeable physicians.

2. KNOWLEDGEABLE POLICY-MAKERS

The human and economic impact of Alzheimer Disease and related dementias, and its toll on society, will be understood.

- Policy and decision-makers are aware of the impact and implications of Alzheimer Disease and related dementias on public policy.

3. INCREASED COMMITMENT TO RESEARCH

Individuals affected by Alzheimer Disease and related dementias will benefit from research.

- Strong support for ongoing clinical and psychosocial research to improve practices and services throughout the progress of Alzheimer Disease and related dementias.
- Strong support for ongoing research into treatment, prevention and cure.

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THE NEED FOR A VISION FOR PUBLIC POLICY

The Alzheimer Society believes that there can be a better life for people affected by Alzheimer Disease and related dementias.

Favourable public policy can significantly improve the quality of life of people affected by Alzheimer Disease and related dementias. Building on the foundation of *Ontario's Strategy for Alzheimer Disease and Related Dementias* and the Society's own *A Blueprint for Action*, our Vision identifies the Society's strategic direction for public policy for the next three years.

In Ontario, the Alzheimer Society has a responsibility to provide leadership in encouraging and supporting public policy that achieves help for today and hope for tomorrow for people affected by dementia. This includes encouraging and supporting the involvement of people with dementia and their caregivers in all aspects of planning.

THE ALZHEIMER SOCIETY

The Alzheimer Society of Ontario, which began its operations in 1983, is one of 10 provincial Societies affiliated with the Alzheimer Society of Canada. The Alzheimer Society of Ontario's mission is to improve the quality of life of people with Alzheimer Disease and related dementias and their caregivers. It exists to foster conditions that enable Chapters to succeed in accomplishing their missions.

In Ontario, there are 39 local Chapters, each separately incorporated. The Chapters provide a wealth of information, programs and support to individuals, caregivers, family members, health professionals and the public.

Together, we share this Vision to shape the future.

BACKGROUND

In the late 1990's, the Alzheimer Society and other stakeholder groups worked in partnership with the government to create *Ontario's Strategy for Alzheimer Disease and Related Dementias* (the *Strategy*). The Society was successful in ensuring that many of the goals outlined in its own document, *A Blueprint for Action*, were reflected in the *Strategy*. The *Strategy* consists of 10 separate initiatives that address the need for specialized education, services and research to improve the quality of life for people affected by dementia.¹ The Alzheimer Society plays a lead role in the implementation of most of the initiatives.

In September 1999, the Government of Ontario officially launched the *Strategy*. This five-year *Strategy* will end on March 31, 2004. To date, there has been definite progress on achieving the *Strategy's* goal of "improving the quality of life for Ontarians affected by Alzheimer Disease

¹ <http://www.gov.on.ca/citizenship/seniors/english/alzheimer-strategy.htm>

and related dementias”. If that goal is to become a reality for all those affected by dementia, much still remains to be accomplished.

IMPACT AND IMPLICATIONS OF ALZHEIMER DISEASE AND RELATED DEMENTIAS

The Disease

Alzheimer Disease is the leading cause of dementia – the name for a group of symptoms that include loss of memory, judgment, reasoning and ability to communicate and function. It is a degenerative and irreversible disease. On average the disease progresses over 8 - 12 years, eventually causing complete dependency on others and finally death. Other diseases causing dementia include vascular dementia, Lewy Body Type, Frontal lobe and Pick’s Disease.

Dementia takes a heavy economic and psychosocial toll on society. It is a prolonged and complicated condition that affects each person differently. All people with dementia have complex needs that change over the course of the disease and require an evolving range of services and supports.

Although new drug treatments are showing promise in treating the symptoms, there still is no known cause, prevention or cure for Alzheimer Disease.

The Numbers

One in 13 Canadians over the age of 65 currently has Alzheimer Disease or a related dementia. Dementia is age-related. Thirty-four percent of people aged 85 or older have dementia, but for people aged 65 to 74 the proportion is 2.5 per cent. The profound impact of Alzheimer Disease and related dementias upon society will be heightened by the accelerating prevalence rates of the disease as the population ages.

The latest statistics indicate that the numbers of those with dementia in Ontario will grow 40 per cent between 2000 and 2010. This projection is conservative. People in the early stages of dementia are not included. As well, the projection only reflects individuals who are over the age of 65 and does not capture the number of younger people who are living with dementia. The first of the post-war “baby boomers” will begin turning 65 in 2011. In less than 25 years, the number of Ontarians with dementia will grow to 307,000, equal to the population of the Windsor area.^{2 3} These numbers do not include the family members, colleagues, neighbours or friends who must also cope with the effects of Alzheimer Disease or a related dementia. The Alzheimer Society of Ontario estimates that 10 people are affected for every person with dementia. In 10 years, almost two million people will be affected by dementia.

² Hopkins R., Hopkins J., PPPC Mental Health Services, Kingston, Ontario, “Dementia Projections for the counties, regional municipalities and districts of Ontario (incorporating CHSA prevalence data)”. Geriatric Psychiatry Programme Clinical Research Bulletin, No. 13, January 2002.

³ Statistics Canada, <http://www12.statcan.ca/english/Profil01/PlaceSearchForm1.cfm>

The Human Impact

Alzheimer Disease and related dementias have a profound affect on every aspect of life for those with the disease, their caregivers, family and friends. This disease affects jobs, finances, retirement, and physical and emotional health, particularly as approximately 50 per cent of people with dementia live in the community and almost all receive care from family or friends.⁴ The care of individuals with any kind of dementia represents one of the greatest challenges to health and social services.

Future dementia growth coupled with continuing changes in family roles and structures will place increasing pressures on the caregiving situation. For the family and friends who provide ongoing, unpaid care and support to persons with dementia, the responsibilities can become overwhelming, especially if they provide care 24 hours a day, seven days a week. Caregivers of people with dementia are at substantial risk for physical and emotional illness. Wives and daughters constitute the majority (66.8 per cent) of all caregivers. Although a large number of caregivers are themselves older adults, one-third of caregivers report having children living at home.⁵ On average, caregivers reported providing care and support for over five years, one-third entirely on their own.

The Economic Impact

The annual societal cost to care for an individual with Alzheimer Disease and related dementias increases significantly with the severity of the disease. In 1998, the cost per person in Canada was estimated to be between \$9,451 and \$36,794.⁶ In 1994, over \$5.5 billion a year was spent on people with Alzheimer Disease and related dementias in Canada.⁷

The most significant components of care that contribute to the societal financial burden are long-term institutional care and paid and unpaid care for assistance with activities of daily living in the community.⁸ Caregivers, who are not paid, often face significant costs in addition to the cost of caring for the person with dementia, such as lost income and extra medical costs for themselves.

⁴ Canadian Study of Health and Aging Working Group. "Canadian Study of Health and Aging: Patterns of Health & Aging or people with dementia in Canada." *Can J Aging* 1994;13:470-487
<http://www.uottawa.ca/academic/med/epid/core3.htm>

⁵ Smale, B., Depuis, S., "Highlights: Preliminary results from the study on Needs of Caregivers of Persons with Alzheimer Disease and Related Dementias and Community Support Services in Ontario." Murray Alzheimer Research and Education Project, University of Waterloo, Alzheimer Society of Ontario, Caregivers Association of Ontario.

⁶ Hux M. et al., "Relation between severity of Alzheimer Disease and costs of caring". *Can Med Assoc J* 1998; 159(5).

⁷ Ostbye T., Cosse E., "Net Economic Costs of Dementia in Canada". *Can Med Assoc J* 1994; 151(10): 1457-64, and personal communication between Alzheimer Society of Canada with the Canadian Study of Health and Aging.

⁸ Hux M. et al., "Relation between severity of Alzheimer's disease and cost of caring". *Can Med Assoc J* 1998; 159(5): 457-65

The Health Care System

Over the last decade, the delivery of health services has changed greatly. The challenges facing service providers and the service delivery system are increasingly complex and require innovative and collaborative efforts to meet the needs of individuals with Alzheimer Disease and related dementias and their caregivers.

If a diagnosis is made while still in the early stages of dementia, and information and support are provided, the individuals and their caregivers can, and often do, cope quite well for the initial period. Drugs are now available that treat some of the symptoms of Alzheimer Disease. Often individuals and caregivers, however, do not receive help from a physician early enough in the disease process. Unfortunately, it is often a crisis that provides the first link to service.

The gap between the need for care and the availability of services continues to grow. Policies and criteria often do not address the unique needs of people affected by dementia. People with dementia occupy two-thirds of the beds in long-term care facilities, yet facilities are frustrated by not having adequate resources to provide the care required. Community Care Access Centres have finite resources and struggle to balance the needs of the continuously increasing stream of people with complex and acute care needs with the ongoing needs of people with long-term requirements, like people affected by dementia.

In the community sector, inadequate staffing levels, low wages, part-time or casual hours, poor or nonexistent benefits and lack of recognition make it increasingly difficult to attract and retain qualified staff. The long-term care facility sector also faces a number of challenges to attracting and retaining qualified staff. In many communities across Ontario, people affected by dementia are unable to find a primary care physician. Access to specialists is even more difficult.

Many people with dementia and their families prefer to remain together as long as possible. The service gaps make this difficult. Services must support people to live as independent and normal a life as possible. In order to postpone institutional placement and prevent or alleviate caregiver burnout, a comprehensive and co-ordinated range of quality care and housing options are needed for individuals throughout the progress of the disease. In particular, a full range of respite options for the caregiver must be available.

Alzheimer Disease must be a research priority. The magnitude of Alzheimer Disease and its impact on society will steadily increase as the population ages. Any intervention that will delay the onset of symptoms of Alzheimer Disease will have an enormous impact on the lives of individuals and the health care system.

TRANSLATING THE ALZHEIMER SOCIETY OF ONTARIO'S VISION INTO PUBLIC POLICY

1. APPROPRIATE SERVICES THROUGHOUT THE DISEASE PROCESS

Individuals affected by Alzheimer Disease and related dementias and their caregivers will have access to appropriate services throughout the disease process.

Province-wide access to appropriate services and improved service co-ordination and integration.

- Adequate, appropriate, timely and affordable individualized assessment, support and services.
- Sustainable funding to support a continuum of high quality programs and services.
- An integrated system, locally, regionally and provincially, facilitated by Dementia Networks.

Environments that support quality of life.

- All settings where individuals with dementia reside or receive care will maintain or enhance the person's quality of life.
- A range of quality housing options available to individuals with dementia throughout the progress of the disease.
- Adequate and consistent licensing, regulation and/or certification of organizations providing residential, health and long-term care services and of the people that they employ.

Access to knowledgeable staff.

- Dementia-specific core learning competencies and educational qualifications identified for staff working directly with individuals affected by Alzheimer Disease and related dementias.
- Adequate dementia content in college and university curricula.
- Incentives for staff and employers to pursue dementia-specific education.
- Provincial standards for dementia training.

Access to knowledgeable physicians.

- Access to knowledgeable primary care and specialist services throughout the province.
- Increased dementia content in medical school curricula.
- Locally-based options for physicians to increase knowledge and confidence in caring for people affected by dementia.

2. KNOWLEDGEABLE POLICY-MAKERS

The human and economic impact of Alzheimer Disease and related dementias, and its toll on society, will be understood.

Policy and decision-makers are aware of the impact and implications of Alzheimer Disease and related dementias on public policy.

- Policy-makers, health care professionals and stakeholders understand the impact and implications of Alzheimer Disease and related dementias on the individuals affected and on society.
- Government and other organizations recognize that the Alzheimer Society is the leading source of information on public policy issues related to dementia.

3. INCREASED COMMITMENT TO RESEARCH

Individuals affected by Alzheimer Disease and related dementias will benefit from research.

Strong support for ongoing clinical and psychosocial research to improve practices and services throughout the progression of Alzheimer Disease and related dementias.

- All individuals affected by Alzheimer Disease and related dementias benefit from a broad range of co-ordinated research.
- Research results are widely disseminated and used to continuously improve practices and services.
- Practices and services are evaluated and the results disseminated and integrated into policy and practice.
- Research agenda developed and promoted through Ontario's Research Coalition.

Strong support for ongoing research into treatment, prevention and cure.

- Sustainable funding for research into treatment, prevention and cure for Alzheimer Disease.
- Research results are broadly disseminated and used to continuously improve practice.

Acknowledgement

Shaping the Future: help for today and hope for tomorrow for people affected by Alzheimer Disease and related dementias was developed by the Alzheimer Society of Ontario's Public Policy Advisory Committee. The Committee has representation from all five of the Alzheimer Society areas in Ontario and includes staff and volunteer leaders from eight Chapters:

- the Alzheimer Society of Chatham Kent,
- the Alzheimer Society of Haldimand-Norfolk,
- the Alzheimer Society of Kenora and District,
- the Alzheimer Society of London and Middlesex,
- the Alzheimer Society of Ottawa,
- the Alzheimer Society of Peel,
- the Alzheimer Society of Thunder Bay and
- the Alzheimer Society of York Region.

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