

# **Ontario's Strategy for Alzheimer Disease and Related Dementias PREPARING FOR OUR FUTURE**

## **EXECUTIVE SUMMARY**

Alzheimer Disease is the most common dementia affecting elderly people, although it has also been diagnosed in those as young as 40. It is a deteriorating brain disease that eventually kills. In Ontario, more than 100,000 people live with the disease, 90 per cent of whom are over the age of 65. With Ontario's growing and aging population, it is expected that Alzheimer Disease and related dementias will increase significantly in coming years.

The Ontario Government promised to listen carefully to those affected by Alzheimer Disease and respond with a co-ordinated strategy to address this devastating disease. The resulting Alzheimer Strategy — the first of its kind in Canada — is the result of broad consultation with key stakeholders across the province. Over 180 submissions were received in response to the government's draft strategy released March 4, 1999.

Ontario's unprecedented multi-year investment of \$1.2 billion in long-term care services has already led to increased service for individuals and families coping with the effects of Alzheimer Disease and related dementias. The Alzheimer Strategy is an important, complementary step and outlines the government's action plan to better meet the needs of Ontarians with Alzheimer Disease and related dementias, as well as their caregivers and families.

The Ontario Government will invest \$68.4 million in this comprehensive, multi-faceted strategy over the next five years.

## **ACTION PLAN HIGHLIGHTS**

### **1. Staff Education and Training \$1.1 million per annum**

- Annual training program open to staff of each long-term care facility and Community Care Access Centre, and staff in Adult Day Programs and supportive housing serving people with Alzheimer Disease.
- A task force will be struck to assess additional training approaches such as video conferencing and Internet-based learning.

### **2. Physician Training \$0.5 million per annum**

- Family doctors will have the opportunity to receive training to assist them in the early detection and diagnosis of Alzheimer Disease and related dementias, optimal prescribing practices and how best to use local community services.

### **3. Increase in Public Awareness, Information and Education \$1.1 million initially, rising to \$1.8 million per annum in 2000/2001 and onward**

- Hiring of one public education co-ordinator for each of Ontario's 39 local Alzheimer Societies to raise awareness of the disease, recruit volunteers, develop and facilitate caregiver support groups and coordinate training events.

**4. Planning for Appropriate, Safe and Secure Environments  
\$0.05 million per annum**

- The government will finance and co-host annual conferences with the Alzheimer Society of Ontario and the Murray Alzheimer Research and Education Project to explore the creative and functional design of living space for people with Alzheimer Disease and related dementias, as well as optimal models of care and appropriate improvements in home environments.

**5. Respite Services for Caregivers  
\$3 million initially, rising to \$7 million per annum in 2000/2001 and onward**

- The province will fund the creation of new Alzheimer day program spaces and the expansion of Alzheimer volunteer respite programs.
- From April 1995 to March 1998, the government increased annual spending on long-term care community services by \$225 million. From April 1998 to March 2006, annual spending on long-term care community services will increase by an additional \$551 million.

**6. Research on Caregiver Needs  
\$0.1 million in 1999/2000, \$0.4 million in 2000/2001**

- The research will determine what key community support services are needed by caregivers. Results will be used to determine how to expand community support services in the future.
- The province will explore opportunities for private sector partnerships for this research grant.

## **7. Advance Directives on Care Choices**

**\$0.05 million in 1999/2000, \$0.65 million in 2000/2001**

- A broad consultation with key stakeholders will be held on a provincial policy on advance directives for care choices.
- Following the consultation, educational materials will be produced and appropriate training will be provided to ensure consistency in the policy's application.
- Completion of an advance directive on care choices will be voluntary and will not be a requirement for admission to any provincially funded health care facility.
- The province will also pursue private and public sector partnerships for the development and dissemination of educational materials.

## **8. Psychogeriatric Consulting Resources**

**\$2 million initially, rising to \$4.55 million per annum in 2001/2002 and onward**

- New funding to employ 40 experts (with an additional 10 experts in 2001/2002) to advise staff in long-term care centres and community service agencies on how to work with people who exhibit difficult or aggressive behaviour.

## **9. Co-ordinated Specialized Diagnosis and Support**

**Policy review under way — resources to be determined**

- Following consultation, local support networks will be designed to provide Alzheimer clients and families with more consistent and accessible specialized diagnostic and treatment services.
- A coalition of researchers, service providers and associations will be explored to plan and monitor Alzheimer research.

- A collaborative effort is now under way to refine the scope and mandate of specialized geriatric services to make their expertise more readily available to people with Alzheimer Disease and their families.

**10. Intergenerational Volunteer Initiative**  
**\$0.5 million in 1999/2000**

- Funding will support the recruitment, training and support of students in grades 11 and 12 who volunteer with individuals with Alzheimer Disease and related dementias at long-term care centres and community agencies. Students will be consulted to determine how best to acknowledge their voluntary contributions.



# **Ontario's Strategy for Alzheimer Disease and Related Dementias PREPARING FOR OUR FUTURE**

## **1.0 BACKGROUND**

### **1.1 The Alzheimer Strategy — A Collaborative and Consultative Process**

It is with pleasure that the Ontario Government releases the first comprehensive Alzheimer Strategy in Canada. Outlined in this document is the government's 10-point plan aimed at addressing the needs of people with Alzheimer Disease and related dementias and their caregivers. The Ontario Government will invest \$68.4 million in this comprehensive strategy over the next five years.

Ontario's strategy for Alzheimer Disease and related dementias has been three years in the making. The Ontario Government met with and benefited from invaluable feedback from caregivers, service providers, volunteers and professionals across the province — the people who know about the effects of Alzheimer Disease and related dementias on individuals, their families and loved ones. Premier Mike Harris launched this project in June of 1996 and subsequently initiated an Alzheimer Strategy Round Table that included membership from a diverse range of consumers and providers (Appendix A outlines the milestones and consultations that occurred over the three year period from 1996 to 1999).

### **1.1.1 Consultation on the Draft Strategy**

On March 4, 1999, the Ontario Seniors' Secretariat released a draft strategy entitled *Ontario's Strategy for Alzheimer Disease and Related Dementias: A Plan of Action*. Over 180 submissions were received in response to the paper from caregivers, professionals, front line service providers and volunteers. Thank you to everyone who took the time to respond with detailed, thoughtful comments. Special thanks is due to the Alzheimer Society of Ontario which co-ordinated and synthesized the responses from all 39 local Alzheimer Societies — reflecting the first-hand knowledge, experience and commitment of its members province-wide. This, in combination with the Alzheimer Society of Ontario's March 1998 "Blueprint for Action", contributed a great deal to the development of the provincial strategy.

The overwhelming support for the government's 10-point action plan was very encouraging:

1. Staff Education and Training
2. Physician Training
3. Increased Public Awareness, Information and Education
4. Planning for Appropriate, Safe and Secure Environments
5. Respite Services for Caregivers
6. Research on Caregiver Needs
7. Advance Directives on Care Choices
8. Psychogeriatric Consulting Resources
9. Co-ordinated Specialized Diagnosis and Support
10. Intergenerational Volunteer Initiative

Section 2 of this document provides the details of each initiative, including government funding to implement each one.

### ***1.1.2 What Respondents Said***

Overall, the 10 elements of the strategy were overwhelmingly endorsed. The submissions from community organizations, professional bodies and individuals provided excellent information and suggestions to assist with the implementation of the initiatives. As a result, much of the feedback from stakeholders has been incorporated into the final strategy outlined in Section 2 of this document.

A multi-disciplinary approach to many of the initiatives with extensive co-operation and collaboration among the key players was strongly recommended. Many of the respondents wanted to be actively involved in the implementation stages of the strategy.

Many respondents indicated that the implementation of the strategy should be flexible and that it should take into account advances in diagnostic techniques, drug treatments and research findings over time. Ongoing review and evaluation of each element must be integral to the strategy.

Before flowing funds for new initiatives, existing research, innovations, programs and services need to be considered to avoid the duplication of services.

Respondents strongly supported the convening of an Alzheimer Strategy Round Table of external stakeholders to oversee the implementation of the strategy and monitor results.

Many respondents also confirmed that sensitivity to the cultural, ethnic and geographic diversity of the province is critical to ensuring fair and appropriate access to services and supports.

The Ontario Government's strategy presents a plan of action to deal with the demands this disease places on our citizens and our health care resources. It presents the building blocks upon which we will improve services for those with the disease and their caregivers. This strategy will challenge us to re-think, reorganize, and re-double our efforts to deal with this growing problem within our families, among our neighbours, and in society as a whole.

## **1.2 Alzheimer Disease and Its Impact on Society**

### **1.2.1 *What are Alzheimer Disease and Related Dementias?***

The following description, for the purposes of this paper only, will help us understand the disease in general and help place the Ontario Government's comprehensive 10-point action plan in context. Information on Alzheimer Disease and related dementias is available in more detail through health care professionals and local Alzheimer Societies (Appendix B lists local Alzheimer Societies in Ontario).

Dementia involves a decline in intellectual abilities which is usually progressive and severe enough to cause significant functional impairment. Alzheimer Disease is the foremost cause of dementia. It is a progressive, degenerative brain disease with no known cause or cure and is considered a terminal illness. Other causes of dementia may include vascular dementia due to stroke, Dementia of the Lewy Body Type, Parkinson's Disease, Pick's Disease and Huntington's Disease.

Alzheimer Disease is a difficult journey for those who have the condition, and for family and friends who care for them. It causes a chronic, relentless, progressive deterioration in all functions, starting with short-term memory loss and impaired language and judgement, and eventually leads to complete disability and death. Many people develop a wide range of behavioural problems that dramatically increase the burden on caregivers. Individuals with Alzheimer Disease may also have an unrelated chronic condition or an acute illness for which they require medical treatment. When an older adult is exhibiting memory loss, the first challenge is to rule out other causes of this problem.

In developing an Alzheimer strategy, it is important to remember that the disease progresses through stages and may include other complicating health factors. Different types of services or modifications to services will be required at different stages of the disease. Social supports, as well as medical services, are required at every stage of the disease.

### 1.2.1(i) *Early/Mild Dementia*

In the early stages of Alzheimer Disease, the person may experience mild impairment in his or her ability to function independently. Many people are unaware of the impact of the disease in these early stages. If asked about their memory, most would reply that they do not have a problem. This lack of insight on the part of those with Alzheimer Disease can be problematic and result in them interpreting attempts to provide assistance as intrusive and unnecessary.

In the early stages, the person may have short-term memory loss and difficulty finding words. These problems, although inconvenient, do not affect independence or autonomy for the most part. The person can manage the practical activities of daily living and even complex tasks like banking, driving, shopping and cooking. The goal of a care plan at this stage is to help the person maintain independence and autonomy safely and as long as possible. Simple strategies like calendars, medication dispensers, reminders, lists, automatic kettles or automatic bill paying through a bank can help the person live in the community as independently as possible.

During this stage, planning ahead is essential. Each person should consider the option of designating, through a Power of Attorney, a substitute decision-maker for health and personal care as well as for financial management. Each person should be encouraged to make a will as well as to outline his or her particular individual preferences for care in the future. One way for people to stipulate the type and level of care they wish to receive at a future point in their illness is through the use of advance

directives, which in this paper will now be described more accurately as “advance directives on care choices”. Advance directives on care choices provide a format for individuals who are still mentally competent to make their wishes known and exercise their right to make decisions about their future personal health care choices. These directives can complement Powers of Attorney for Personal Care.

Individuals and family members may wish to obtain information on the disease, advance directives on care choices, and the services available by calling a local Alzheimer Society (Appendix B lists local Alzheimer Societies across Ontario).

#### *1.2.1(ii) Middle/Moderate Dementia*

The person in the middle stages of dementia has lost the ability to manage the common activities of daily living including driving, managing finances, remembering medications and shopping and he or she starts to have problems with more basic activities such as grooming, dressing and bathing. The person’s care needs increase significantly. In this stage, behavioural problems may emerge and often peak. Most people are still at home at this time, and most caregivers feel a tremendous burden trying to manage the activities of daily living, dealing with the behaviour problems and perhaps coping with their own medical problems plus the financial, emotional and social stress of this illness.

Family members may wish to contact their local Community Care Access Centre or one of the 39 Alzheimer Societies to learn about services available to them and perhaps to develop a plan of care.

The goal of a care plan at this stage is most often to supplement and assist the family caregiver to manage physical demands like grooming, dressing, shopping and cooking, and to cope with a range of behavioural issues like wandering, agitation, or getting up at night. Caregivers risk becoming angry, depressed, isolated, bitter, hopeless or physically ill themselves and can easily “burn out” at this stage.

Family caregivers live with the person with Alzheimer Disease seven days a week, twenty-four hours a day — they need relief, time out to recharge and relax. Several forms of relief for caregivers are collectively known as respite care. In-home respite, where a paid worker or a trained volunteer comes in to help with housework or just stays with the person who has the disease, allows the caregiver the freedom to go out for a few hours.

Adult Day Programs or “centres” provide another form of respite and time out; 163 such programs in Ontario specialize in serving people with Alzheimer Disease. Day programs provide planned activities for participants geared to their interests and functioning level. Inclusion of a new participant often requires a few short visits to the centre before full-time participation is comfortable for everyone concerned.

Respite care in a long-term care facility for a few days or weeks to give caregivers a well-deserved break is often necessary at this time.

The goal of a care plan at this stage is to help caregivers cope and enable the person to stay in his or her home as long as possible.

Clients and caregivers may require a whole range of assistance from simple caregiving and homemaking to occupational therapy, dietician services, nursing, physiotherapy and personal support. Patients and caregivers also require physicians who are familiar with the disease to manage the psychiatric, emotional and often complex and vexing behavioural problems. In this stage, placement in a long-term care facility may be discussed and planned with a case manager from the nearest Community Care Access Centre (Appendix C lists Community Care Access Centres across Ontario).

### *1.2.1(iii) Late/Severe Dementia*

In this stage, the person with the disease needs assistance with washing, dressing, toileting, and feeding. The person's care needs are often too heavy for the caregiver, so long-term care facility placement may be required. Almost half of Ontario's current 57,000 long-term care residents have some form of dementia. Long-term care facilities that have been specifically designed for persons with Alzheimer Disease are desirable, allowing residents maximum freedom along with safety. For example, in this stage, people with Alzheimer Disease who are still mobile can wander out of a facility if it is not secure. If this is the case, people with Alzheimer Disease are sometimes restrained in other ways to prevent them from wandering outside. Physical and chemical restraints reduce function and increase disability, diminishing the person's dignity and quality of life. Other persons

in late stage dementia may be non-ambulatory, unable to sit up independently and/or hold their head up. The careful design of a person's environment is clearly important to address the varying needs of people with Alzheimer Disease and to assist in the management of their disease.

#### *1.2.1(iv) Reversible Dementia*

The term, “reversible dementia”, is used for a cognitive disorder where normal or nearly normal functioning can be restored. The potential to reverse or delay deterioration emphasizes the importance of early diagnosis of reversible dementia. Cognitive impairment from depression, delirium and drugs can be reversed with appropriate diagnosis and treatment. It is essential to rule these out as early as possible.

Up to 50 per cent of people with early dementia have co-existing depressive symptoms at some point in their illness. Nevertheless, treatment of depression often results in dramatic and significant improvement in function and quality of life. Delirium is an acute state of confusion often resulting from severe illnesses. It can be difficult at times to differentiate between dementia and depression.

Some medications can cause dementia-like states. Some prescription drugs and over-the-counter products can cause memory loss. All medications should be carefully assessed by a health professional, and alternative treatments explored if a medication is suspected of causing dementia-like symptoms.

### **1.2.2      *The Importance of Early Detection***

Ruling out or diagnosing co-existing problems like depression and delirium that may be readily treated is extremely important. Also, proper screening, early assessment, and diagnosis may reduce the need for people to take other tests such as electroencephalograms (EEGs), computerized axial tomography (CAT scans) or magnetic resonance imaging (MRIs).

Although the prospect of an early cure for Alzheimer Disease is still remote, the recent advances in treatments to slow the progress of the disease and reduce its symptoms also support the value of early diagnosis and treatment. The growing number of people with the disease demands greater efforts to reduce or delay the effects of this disease and minimize the disability it causes. Early diagnosis provides families and caregivers with an understanding of what to expect, and allows time for them to prepare to manage the disease. Timely interventions should be introduced to maximize the person's function and quality of life and minimize stress, anxiety and caregiver burden.

Specialists who have training in the area of Alzheimer Disease and related dementias are knowledgeable in the assessment, diagnosis and treatment of the diseases. As well, tools such as the Folstein Mini-Mental State Examination — a reliable, abbreviated cognitive screening examination — are available for use by a variety of health care professionals. With the projected aging of our population and longer life expectancies, physicians will be required to be more familiar with the health needs of older adults and

highly specialized diagnosis and treatment will need to be more readily available (section 2 of this document provides details of initiative #9 — Co-ordinated Specialized Diagnosis and Support).

### **1.2.3      *Prevalence of Alzheimer Disease and Related Dementias***

Alzheimer Disease is the most prevalent dementia, representing two-thirds of all cases of dementia in the elderly. According to the *Canadian Study of Health and Aging*, over 117,000 people in Ontario have Alzheimer Disease and other dementias (Canadian Medical Association, 1994). Age is the most significant and easily identifiable risk factor for dementia (approximately 90 per cent of cases are over age 65) although it can occur in middle-aged and younger adults. The number of Ontario's population over the age of 65 will increase dramatically in the near future. This will lead to a significant increase in Alzheimer-related dementias placing increased demands on families, friends and our health care and social service systems to deal with the unique needs of these individuals.

By 2010, the actual number of moderate and severe cases of dementia will increase by 85 per cent and by 2021 the increase will be 150 per cent. The number of people with Alzheimer Disease and related dementias in Ontario in 1999 is estimated to be 117,000. In Canada, the number is expected to increase from an estimated 300,000 in 1999 to 750,000 by 2031. This substantial increase in cases of dementia among the elderly population is caused in part by longer life expectancies and the higher rates of dementia in

later life. For example, one in 13 Canadians over the age of 65 currently has Alzheimer Disease or a related dementia and over 40 per cent of people aged 90 or more have some form of dementia. The problem is obviously growing with our seniors population, so planning for the future must begin now.

#### **1.2.4      *Caring for the Caregivers***

Generally, of the care provided to people of all ages and for any health-related reason, 80 to 90 per cent is provided by unpaid caregivers such as family members, partners, friends, neighbours and volunteers.

Caring for a family member often places extraordinary demands on caregivers and can have considerable consequences for them. For example, many women have to juggle raising children with work outside the home and care for aging parents. Another familiar example is that of older spouses who, while caring for a loved one with Alzheimer Disease, acquire health problems themselves.

In 1996, the American Alzheimer Association presented results from a study of caregivers of people with Alzheimer Disease. These findings reported:

- 96 per cent of caregivers said caring for loved ones is a "labour of love"
- at the same time, respondents described caring for their loved one as "frustrating" (90%), "draining" (87%), and "painful" (87%)
- caregivers spent, on average, 69 to 100 hours per week caring for their loved ones

- 49 per cent of caregivers reported that they have made financial sacrifices in order to better care for their loved ones
- 31 per cent of those caring for people with a severe case of Alzheimer Disease reported that their finances had been "greatly affected" by their caregiving responsibilities

Caregiving is the theme for the Alzheimer Society's 1999 Awareness Campaign and the Alzheimer Society of Canada has released "10 Signs of Caregiver Stress." This brochure and other information on caregiver stress and how to reduce it are available through local Alzheimer Societies.

### **1.3 Summary**

The statistics on Alzheimer Disease, together with our aging population, while significant on their own, can only begin to tell the story of the far-reaching impact that Alzheimer Disease has on individuals, on families, and others who care for, and about, people with the disease. The impact of this insidious disease on individuals, caregivers, families, health care professionals and the health care system is enormous. The social and economic impact of this disease will increase as the population ages.

In response to this challenge, the Government of Ontario has made a commitment to work in partnership with the provincial and local Alzheimer Societies, service providers and numerous interest and consumer groups, to implement a comprehensive provincial Alzheimer strategy for the future, making the Province of Ontario a leader in this field.

## **1.4 What is Ontario Doing Now for People with Alzheimer Disease and Related Dementias?**

The government recognizes the evolving needs of our growing and aging population and is responding by enhancing access to long-term care and health services. Currently, the Ontario Government has a considerable investment in services for people with Alzheimer Disease and related dementias and this commitment is being expanded.

On April 29, 1998, the Ontario Government announced a Long-Term Care Multi-Year Investment Plan — the largest expansion of health services in Ontario history. Starting in fiscal year 1998/99, the Government of Ontario will increase its annual long-term care spending by \$1.2 billion to improve long-term care programs such as in-home services, community support services and long-term care facilities (nursing homes and homes for the aged). This expansion is important because although exact numbers are unavailable, a considerable proportion of individuals with Alzheimer Disease are served by these programs.

There are 38 long-term care service areas across the province. Over the next seven years, all areas will receive additional community funding so that each will have its fair share, based on the size, age and gender of its population. Furthermore, 34 of the service areas will receive more long-term care facility beds to fairly distribute these resources in relation to Ontario's population over 75 years of age.

Throughout the course of this multi-year plan, as new demographic information on our service areas becomes available, the government will ensure that community funding and new long-term care beds are appropriately targeted to the areas with the greatest need. Through our population-based funding formulae, distribution of new beds and funding for community services will be adjusted over time based on actual population growth in each area and the actual characteristics of each area's population.

#### **1.4.1      *Personal Support Worker Training***

The Personal Support Worker Training Program was developed as part of the Ontario Government's plan to reform long-term care and support services provided to people living at home and in long-term care facilities.

It is a single training program that consolidates and enhances the traditional courses of Health Care Aide Training, Home Support Training levels 1, 2 and 3, Attendant Care Training and Respite Care Training.

Last year, an additional \$3,282,000 was announced for the Personal Support Worker Bridging Program, bringing the total allocation for 1998/99 to \$10 million. The funding will be available for the next five years and will be used to upgrade the skills of existing workers to meet the requirements of the Personal Support Worker certification. These are workers who provide personal support, homemaking, attendant care, and respite services (section 2 of this document provides more detail).

### **1.4.2 Long-Term Care Facilities**

Current funding levels and recent announcements clearly demonstrate the government's determination to ensure that better quality and more accessible long-term care facility services are in place for all Ontarians who need them, including people with Alzheimer Disease and related dementias.

In 1998/99, the Ontario Government's annual funding for the 57,000 people in long-term care facilities was approximately \$1.3 billion. People with Alzheimer Disease and related dementias make up at least 42 per cent of the 57,000 residents, that is, about 23,940 residents. They will constitute an ever-growing percentage of residents in long-term care facilities as the rate of moderate and severe cases of dementia increases substantially in the years to come.

In April, 1998, the Government of Ontario announced that approximately \$700 million in funding would be added to the annual spending on long-term care facilities as part of a multi-year expansion. The funding will increase the number of beds and increase nursing and personal care services at a rate that matches the care requirements of residents as measured annually.

It is safely estimated that a significant amount of this \$700 million in new annual funding for Ontario's long-term care facilities will go to serve people with Alzheimer Disease and related dementias.

The investment plan includes the opening of 20,000 new long-term care beds for the first time since 1988. Also, structurally outdated long-term care facilities containing 13,200 beds will be rebuilt to meet new, modern design standards. In addition to the permanent funding increase of \$700 million, an average of \$96 million each year for the next 27 years will be spent to fund construction costs of new facilities and to rebuild outdated ones.

Those who live with or care for people with Alzheimer Disease realize the important link between their immediate surroundings and their general well being. Many caregivers and front line workers are searching for ways to change environments to make those living with Alzheimer Disease more comfortable.

In May of 1999, the Ontario Government, in partnership with the Alzheimer Society of Ontario and the Murray Alzheimer Research and Education Project, co-hosted a conference on optimal design of accommodation for people with Alzheimer Disease. Participants shared the latest information on the impact innovative environmental features can have on the quality of life and behaviour of people with Alzheimer Disease (section 2 of this document provides more detail).

Since 1996, the provincial government has worked together with long-term care facility provider associations (the Ontario Nursing Home Association and the Ontario Association of Non-Profit Homes and Services for Seniors) and consumer associations to develop design standards for all new long-term care facilities. These design standards are among the highest in North America.

Some of the design standards or mandatory requirements that must be incorporated into the design of each long-term care facility include:

- a maximum of 32 residents in each resident home area
- a move from three and four-bed wards to single and double accommodations
- barrier-free washrooms that promote resident privacy, dignity and independence
- convenient and accessible storage space
- shorter corridors

These standards ensure a more “home-like” atmosphere and recognize the special needs of people living in long-term care facilities.

The facilities to accommodate 20,000 new beds must comply with the new design standards. In addition, older outdated facilities containing 13,200 existing beds will be rebuilt to conform to the new design standards.

Many of the new proposals to build long-term care facilities submitted in the Ministry of Health and Long-Term Care’s Request for Proposals process include design commitments that surpass the new design standards.

### **1.4.3 Community Services**

While we know that a large number of people with Alzheimer Disease and related dementias are served by Community Care Access Centres and community support service providers, there are no definitive figures on the number who benefit from these services.

Community Care Access Centres arrange for and purchase services (nursing, occupational therapy, physiotherapy, social work, dietetics services, speech-language pathology, homemaking and personal care) to be provided in the person's own home. In addition, Community Care Access Centres are responsible for all placements in long-term care facilities. In the future, Community Care Access Centres will be responsible for admission to community Adult Day Programs, including those that specialize in dealing with people with Alzheimer Disease and related dementias.

Other community services funded by the Ministry of Health and Long-Term Care which are provided by community service providers include meal services, transportation, home maintenance, friendly visiting, attendant services (homemaking and personal support), caregiver support services, supportive housing and Older Adults Centres.

Long-term care community services are available to anyone who needs them for any legitimate reason. Service providers record the type of problem a client has and the type of service they receive. For example, records will show someone needs assistance with bathing and dressing and receives the service of a homemaker.

The Ministry's long-term care funding for caregiver support services (such as counselling, training, information, and respite) was \$13 million in 1996/97, serving over 47,000 clients, and was increased to \$14.8 million in 1997/98, serving 48,500 clients.

From 1995/96 to 1999/2000 the Ontario Government has announced an increased investment in community services of \$346.9 million. Of that investment, \$88.9 million was specifically targeted for services like Adult Day Programs and respite services that benefit, but are not limited to, persons with dementias.

In April of 1998, the Ontario Government announced that a further \$550.8 million new dollars (from the \$1.2 billion multi-year investment plan) will be added to the annual budget for community services over the next eight years, beginning in fiscal year 1998/99.

Programs and services that specifically focus on clients with Alzheimer Disease are as follows:

**Adult Day Programs — serving persons with Alzheimer Disease exclusively**

1999/2000 base budget: \$11.5 million

Number of programs: 57

Number of clients served: 10,000

**Adult Day Programs — integrated service for persons with Alzheimer Disease as well as frail elderly clients**

1999/2000 base budget: \$14.5 million

Number of programs: 85

Number of clients served: 9,000

**Psychogeriatric Outreach Teams (excluding outreach services funded through the provincial psychiatric hospitals and specialized psychiatric hospitals) — serving people with mental illness, Alzheimer Disease, related dementias and other psychogeriatric problems**

1999/2000 base budget: approximately \$9.9 million

Number of outreach teams: 27

As part of the \$170 million commitment announced in March, 1996, and the \$1.2 billion announced in April, 1998, a total of over \$1.3 billion new dollars have been added to the budgets of several local Alzheimer Societies.

In 1998/99, the total Ministry of Health and Long-Term Care funding to Alzheimer Societies in Ontario was \$3.6 million.

#### **1.4.4      *Drug Therapies***

The drug Aricept has been listed, effective June 1, 1999, as a “Limited Use” drug on the Ontario Drug Benefit (ODB) Formulary. Both the National Alzheimer Society of Canada and the Alzheimer Society of Ontario support the addition of Aricept to the Formulary. It is the first of the drugs on the market to treat the symptoms of Alzheimer Disease to be included in the Formulary. Ontario is the first province to make this drug available through a provincial drug plan.

The drug treats mild to moderate symptoms in the early stages of Alzheimer Disease. It is not a cure and its effect is limited both in terms of who will benefit from it and how long the benefit will be sustained. As a result, Aricept has been added to the Formulary as a “Limited Use” drug. For more information on this “Limited Use” drug, individuals should contact their family physician.

The development of new drugs that may prove more effective for a longer period of time is anxiously awaited. As new drug products to treat Alzheimer Disease and related dementias emerge, their potential benefit will be closely studied by the Provincial government. Once new drugs receive the “Notice of Compliance” and “Drug Identification Number” from the federal government, they can be considered for inclusion in the Ontario Drug Benefit Formulary. The Ministry of Health and Long-Term Care relies on an expert panel called the Drug Quality Therapeutics Committee for advice on which drugs should be added to, or deleted from, the Formulary.



## **2.0 THE ONTARIO ALZHEIMER STRATEGY ACTION PLAN**

The Alzheimer Strategy Action Plan lets us prepare now for the increasing burden caused by this disease and establishes a framework for those who provide care and services for people who have Alzheimer Disease and other dementias.

Over our lifetime, the vast majority of us will come in contact with Alzheimer Disease. While this disease presents a challenge, it also provides us with an opportunity to use our resourcefulness, humanity and commitment to each other to make this journey as dignified and meaningful as possible. This action plan challenges all citizens of Ontario to learn more about Alzheimer Disease and become involved.

The government will invest \$68.4 million in this comprehensive strategy over the next five years.

### **1. STAFF EDUCATION AND TRAINING \$1.1 million per annum**

#### **Strategy**

In 1998, for the first time, a staff member from nearly all of Ontario's 498 long-term care facilities received five days of intensive training to enhance their ability to meet the care requirements of residents with complex cognitive disorders. The training, which focused on dementias including

Alzheimer Disease, will be evaluated on an ongoing basis. The response to date has been extremely favourable.

The Ministry of Health and Long-Term Care will proceed with this training annually, keeping in mind the importance of linking all education components — public awareness and training of front line staff and medical professionals — so that they are complementary and result in consistent approaches to care. The government's commitment of \$1.1 million annually includes replacement staff costs.

The objectives of the training will be to help front line staff to:

- develop a skill set which incorporates sensitivity and respect for the individuality of each resident
- understand appropriate assessment tools (e.g., Folstein Mini-Mental State Examination)
- plan, implement and evaluate care strategies for residents with psychogeriatric needs and foster strategies to support the team, families/partners and volunteers as they provide care and services to residents with psychogeriatric needs

This extensive training program will be open to staff in each of the 498 long-term care facilities; each of the 43 Community Care Access Centres located across the province; as well as staff in Adult Day Programs and Supportive Housing Programs serving people with Alzheimer Disease.

While the government will continue the existing training approach for the next scheduled training session, the government is also making a commitment to strike a task force charged with assessing additional training approaches such as video conferencing and Internet-based learning. A plan

to reach as many front line staff as possible, with high-quality training will be the objective of the task force.

The task force will be comprised of a broad range of service providers and associations such as the Alzheimer Society of Ontario, the Murray Alzheimer Research and Education Project, the Ontario Association for Non-Profit Homes and Services for Seniors, the Ontario Nursing Home Association, the Ontario Association of Community Care Access Centres, the Ontario Community Support Association, the Regional Geriatric Programs of Ontario and the Ontario Geriatric Psychiatry Interfaculty Group.

## **2. PHYSICIAN TRAINING** **\$0.5 million per annum**

### **Strategy**

It is clear from consultation feedback that physician training is a key issue. A standardized training program will be developed on the basis of practice outcomes related to dementias. To maintain consistency, the program will build on and complement the other training and public education initiatives in the Alzheimer Strategy. The curriculum will include training in the areas of early detection, use of appropriate assessment tools, prescribing guidelines, and information on local community services.

In the development of the training program, the government will collaborate with the medical community (e.g. geriatricians, geriatric psychiatrists,

neurologists, family physicians and consulting physicians in long-term care facilities). Professionals from across the medical and health care sectors such as representatives from the Ontario College of Family Physicians, the Ontario Geriatric Psychiatry Interfaculty Group, the five university faculties of medicine in Ontario, the Regional Geriatric Programs and the Ontario Medical Association will specifically be asked to take part.

**3. INCREASE IN PUBLIC AWARENESS, INFORMATION AND EDUCATION**  
**\$1.1 million initially, rising to \$1.8 million per annum in 2000/2001 and onward**

**Strategy**

The government will fund one public education co-ordinator at each of the 39 local Alzheimer Societies. The public education co-ordinators will have four primary public awareness and education mandates as follows:

- initiate and maintain public education activities in their area which raise awareness of the disease
- recruit volunteers for local Alzheimer Societies and for long-term care service agencies
- develop and facilitate Alzheimer family caregiver support groups
- co-ordinate training events for volunteers, caregivers, staff and others

A full job description will be developed jointly by the government and the Alzheimer Society of Ontario and will be complemented by mechanisms to measure the effectiveness of the positions.

The government will ask the Alzheimer Society of Ontario to take responsibility for providing the province with a viable work plan to ensure that access to public education is facilitated across the province including geographic areas not currently served by local societies. The Alzheimer Societies will work collaboratively with local organizations and networks to take into account the work of other valuable existing programs such as caregiver support groups.

The Murray Alzheimer Research and Education Project and the Alzheimer Society of Ontario have been requested to submit a proposal to update educational materials to the Ontario Seniors' Secretariat by December 31, 1999.

**4. PLANNING FOR APPROPRIATE, SAFE AND SECURE ENVIRONMENTS**  
**\$0.05 million per annum**

**Strategy**

In May of 1998, the government introduced new design standards for the construction of long-term care facilities and the renovation of older facilities. As a result of the efforts and commitment of a working committee comprised of service provider organizations, consumers, and government representatives, the *Long-Term Care Facility Design Manual — May, 1998*, was developed and widely distributed, in support of the province's commitment to build 20,000 new long-term care beds. Six

thousand seven hundred of those beds were awarded in the fall of 1998 and the Request for Proposals to build another 5,760 long-term care beds was issued in April 1999.

The government is also funding the rebuilding of 13,200 beds in long-term care facilities across the province upgrading them to meet our new design standards.

On September 23, 1998, a very successful conference, co-hosted by the Ontario Government and the Alzheimer Society of Ontario was held on the optimal design of long-term care facilities for residents with Alzheimer Disease and related dementias.

A second design conference held on May 17 and 18, 1999 in Toronto and co-hosted by the Alzheimer Society of Ontario, the Murray Alzheimer Research and Education Project and the Ontario Government was also extremely well attended and received highly favourable reviews. The conference promoted further dialogue on the best environmental design for long-term care facilities serving people with Alzheimer Disease and related dementias.

The recent conference and past work of the joint working committee on design standards are examples of how our Alzheimer strategy can facilitate partnerships and linkages to address important issues and challenges.

Collaboration among all our partners will continue to be encouraged by co-hosting further design conferences on an annual basis for the next four years.

The Ontario Government will continue to cover the travel and registration expenses for up to 80 volunteers to attend each year from across the province.

Future conferences will explore not only environmental design for long-term care facilities but will also address optimal models of care within these improved environments. Appropriate improvements in home environments and supportive housing will also be discussed.

## **5. RESPITE SERVICES FOR CAREGIVERS** **\$3 million initially, rising to \$7 million per annum in 2000/2001 and onward**

### **Strategy**

The Ontario Government clearly recognizes the increasing need for long-term care community services. Giving caregivers a break through respite services is a key support, the value of which has long been recognized by the families of those with Alzheimer Disease.

The government plans to significantly expand adult day program spaces and create new volunteer respite programs for caregivers and clients with Alzheimer Disease and related dementias. In 1999/2000, \$3 million has been earmarked to be used exclusively for these programs. This will be increased to \$7 million per year starting in 2000/2001. Local Alzheimer Societies, together with the Caregivers' Association of Ontario, will link with local communities to advise on the best locations for the new programs.

From April 1995 to March 1998, the Ontario Government increased its annual spending for Community Care Access Centre services (visiting nurses, therapists and homemakers) and other long-term care community services (e.g. Meals on Wheels, Adult Day Programs) by \$225 million. In addition to this investment, the government committed to further increase long-term care services spending by \$551 million as part of the \$1.2 billion multi-year investment in long-term care services, announced in April of 1998. These funds will benefit clients who require homemaking, nursing care, or physiotherapy, and will expand other valuable programs such as Adult Day Programs and respite services. The \$7 million in annual funding specifically for respite services for caregivers comes from the \$551 million investment.

**6. RESEARCH ON CAREGIVER NEEDS**  
**\$0.1 million in 1999/2000, \$0.4 million in 2000/2001**

**Strategy**

Research is needed to determine exactly which supports caregivers need and want. The Government of Ontario will fund a joint project between the Alzheimer Society of Ontario, the Murray Alzheimer Research and Education Project and the Caregivers' Association of Ontario, to ascertain and document the key community support services caregivers need to continue in their invaluable role. The three organizations will submit a proposal by January 31, 2000.

Results from this applied research will guide government decisions on the expansion of community support services. The province's \$551 million plan to enhance community-based programs was announced in April of 1998 as part of the \$1.2 billion investment in the long-term care system.

The project will first review the existing information and research findings on the needs of caregivers, and will build upon this work. Caregivers will be active participants in the research so that the services needed to support them are identified. The need for respite for caregivers has already been identified as critical, but other supports may be just as important, such as coping strategies, counselling, service information, home modification, assistance with financial planning and peer support groups. The province will explore opportunities for private sector participation or partnership in this research grant.

## **7. ADVANCE DIRECTIVES ON CARE CHOICES** **\$0.05 million in 1999/2000, \$0.65 million in 2000/2001**

### **Strategy**

The province will engage consumer advocates, seniors' groups, service providers and other experts to develop a provincial policy in support of advance directives on care choices. This will allow individuals to make their wishes known about future treatment at home, in the physician's office, in community programs, or in any provincially funded health care facility (e.g. hospitals or long-term care facilities). The intent of this initiative is to enhance and protect seniors' rights, enable them to make informed choices and to not leave them vulnerable to the wishes of others.

Advance directives on care choices provide a format for individuals who are still mentally competent to make their wishes for their future personal health care choices known. Advance directives on care choices contain pre-planned and pre-determined personal decisions regarding acute medical procedures and other care decisions.

The Ministry of the Attorney General, the Office of the Public Guardian and Trustee, the Regional Geriatric Programs of Ontario, the Ontario Geriatric Psychiatry Interfaculty Group, the Alzheimer Society of Ontario, the Advocacy Centre for the Elderly and other experts in the area will be invited to play key roles in guideline development and the provision of public education on this issue.

Advance directives on care choices will be a voluntary process for individuals. The completion of an advance directive on care choices will not be a requirement for admission to any provincially funded health care facility.

Current legislation in Ontario was created to protect the rights of individuals. A common and correct understanding of this legislation — the *Health Care Consent Act* and the *Substitute Decisions Act* — and the assurance that individuals' wishes are being carried out in a consistent manner across the province are required. A key element of this initiative will be public education, especially with community agencies and long-term care facilities, in order to clarify responsibilities in this area.

As an initial step, a special session on Advance Directives was sponsored by the Ontario Government at the International Congress on Law and Mental Health on June 16, 1999. Approximately 120 stakeholders were invited to participate. Key issues were raised by the distinguished panellists, which will be addressed by the government in its policy on advance directives on care choices. Subsequent, province-wide consultation with key stakeholders and individuals on the direction the government should take will occur over the fall. A working conference focused on Ontario's specific requirements will be organized early in 2000.

Following confirmation of a provincial policy on advance directives on care choices, the province will fund the development and dissemination of the necessary educational materials to put the policy into effect, and will ensure appropriate training for its application. The province will pursue opportunities for private and public sector partnerships for the development and dissemination of the educational materials.

## **8. PSYCHOGERIATRIC CONSULTING RESOURCES** **\$2.0 million initially, rising to \$4.55 million per annum in 2001/2002 and onward**

### **Strategy**

The government will fund the hiring of additional specialized workers to support front line staff in long-term care facilities and community agencies that serve people who exhibit difficult or aggressive behaviour.

Initially 40 experts with expertise in behaviour management, psychogeriatrics or related experience, will be hired to assist and support

front line staff with these difficult situations. In fact, to ensure that the needs across the province are met in the area of psychogeriatric services, the government will further expand staff resources in 2001/2002 by adding 10 staff over and above the original commitment of 40.

The implementation of this initiative will build on existing resources at the community level. Agencies with a multi-disciplinary approach will be encouraged to participate. Representation from a broad cross-section of health care professionals will be sought including geriatricians, social workers, occupational therapists, nurse practitioners, and in particular, geriatric psychiatrists.

## **9. CO-ORDINATED SPECIALIZED DIAGNOSIS AND SUPPORT** **Policy review under way — resources to be determined**

### **Strategy**

Some people suffering from Alzheimer Disease and related dementias whose conditions are particularly complex require specialized diagnostic and treatment services. Clear, simple, local referral protocols are needed to improve access to specialized services and supports for those who need them.

Over the fall, the government will call together Regional Geriatric Programs and other specialized geriatric experts, the Alzheimer Society of Ontario, and long-term care service provider groups to design local, specialized support networks to serve Alzheimer clients and their families through the front line agencies that support them. This will include the development of

local referral protocols between long-term care facilities, Community Care Access Centres, local Alzheimer Societies and specialized geriatric services.

The province will also explore establishing a coalition among the Alzheimer Society of Ontario, the Murray Alzheimer Research and Education Project, the Regional Geriatric Programs of Ontario, the Ontario Geriatric Psychiatry Interfaculty Group and Ontario's five university faculties of medicine, to plan, co-ordinate and monitor ongoing research in this area.

The government is undertaking a review of specialized geriatric services including Regional Geriatric Programs and will be collaborating with relevant stakeholders to refine their scope and mandate. This review will include, but not be limited to, the number and location of the specialized geriatric services, their funding and accountability.

Ontario's five Regional Geriatric Programs provide a co-ordinated range of specialized geriatric services to frail elderly adults with multiple or complex needs. Other specialized geriatric and psychogeriatric services serve persons whose dementia-related needs are complex. Linkages between the specialized services, primary care physicians and community workers need to be strengthened so that their knowledge and expertise can benefit frail elderly clients in need.

The Ontario Medical Association has indicated an interest in ensuring doctors are serving their aging patients effectively, as well as encouraging some to specialize in geriatrics.

The government recognizes the importance of a multi-disciplinary approach to Alzheimer Disease. The consultation confirmed that access to highly specialized assessment and treatment, including specialists like geriatricians, geriatric psychiatrists and neurologists needs to be organized on a more comprehensive and equitable basis.

## **10. INTERGENERATIONAL VOLUNTEER INITIATIVE \$0.5 million in 1999/2000**

### **Strategy**

The intergenerational volunteer initiative will encourage high school students to volunteer in long-term care facilities and community programs serving people with Alzheimer Disease. Through this initiative, it is hoped that intergenerational communication and understanding will be fostered and that a lifelong commitment to voluntarism will be promoted. Aimed at students in grades 11 and 12 in the year 1999/2000, this initiative will complement the 40-hour community service requirement recently established by the Ministry of Education for high school students over four years starting in September 1999.

The province will provide \$0.5 million for the recruitment, training and support of student volunteers. The Alzheimer Society of Ontario will be encouraged to work with appropriate community organizations and provincial student groups to develop the necessary protocols and educational materials.

Local Alzheimer Societies will have the lead role in promoting this initiative. The public education co-ordinator from each local Alzheimer Society will recruit and arrange for the training of these high school student volunteers and select the long-term care facility or community agency in which they will serve. The local Alzheimer Society, long-term care facility or agency receiving the student volunteer will be encouraged to arrange for transportation for students living in rural areas where distance and public transit would otherwise pose a barrier to their participation.

The province will link with existing volunteer programs to ensure the contributions of existing student volunteers who work with individuals with Alzheimer Disease and related dementias are recognized. Students will be consulted on how best to acknowledge their voluntary contributions.

### **3.0 NEXT STEPS/TIMETABLE**

Some of the initiatives are in the planning stages, and others have already taken important first steps (e.g. the Alzheimer Designs for Quality of Life conference held May 17 and 18, 1999 and the Advance Directives session at the International Congress on Law and Mental Health, June 16, 1999). A comprehensive draft implementation plan for all ten initiatives will be produced and key stakeholders consulted. Some initiatives, such as the public education co-ordinators for local Alzheimer Societies will be funded immediately, some in the very near future, while other action items will require additional planning for how the funding will be distributed.

An Alzheimer Strategy Round Table of external stakeholders will be convened by the Ontario Seniors' Secretariat in the fall of 1999 to provide the government with advice on implementation matters and help identify opportunities to further strengthen each of the 10 initiatives. Careful consideration will be given to the appropriate composition of the round table.

Target dates for the next steps including implementation of the Action Plan are as follows:

| <b>INITIATIVE</b>  | <b>TIMETABLE</b>   |
|--|--|
| 1. Staff Training and Education                            | Development work to commence in September of 1999.<br><br>Five-day training sessions to begin in fall of 1999.   |
| 2. Physician Training                                      | Consultations to begin in the fall of 1999.<br><br>Development work on training modules to start in fall of 1999.  |
| 3. Increase in Public Awareness, Information and Education | Agency funding approved in September 1999 by Ministry of Health and Long-Term Care.<br><br>Hiring and training of public education co-ordinators at each local Alzheimer Society beginning in the fall of 1999.<br><br>The Alzheimer Society of Ontario (ASO) and the Murray Alzheimer Research and Education Project (MAREP) have been asked to submit a proposal to update educational materials to the Ontario Seniors' Secretariat by December 31, 1999. |
| 4. Planning for Appropriate, Safe and Secure Environments  | On May 17 and 18, 1999, the Ontario Government, the ASO and MAREP, co-hosted the second design conference in Toronto.<br><br>Next annual conference planned for May of 2000. (Location to be determined)   |
| 5. Respite Services for Caregivers                         | Specific funding commitments starting in September of 1999.<br><br>Further consultations with local Alzheimer Societies and caregivers' associations to identify criteria for expanded and/or new programs in the fall of 1999.  |

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|---|--|
| 6. Research on Caregiver Needs                    | Joint proposal from ASO, MAREP and Caregivers Association of Ontario to be submitted by January 31, 2000. Research findings will identify key community support services.  |
| 7. Advance Directives on Care Choices             | <p>On June 16, 1999, the Ontario Government sponsored a special session on Advance Directives at the International Congress on Law and Mental Health.</p> <p>Further consultations and a working conference specifically focused on advance directives on care choices in Ontario to be organized early in 2000.</p>   |
| 8. Psychogeriatric Consulting Resources           | <p>Starting in the fall of 1999, Ministry of Health and Long-term Care staff to identify sponsors, commit funds and develop protocols for psychogeriatric services across the province.</p> <p>Forty experts in behaviour management/psychogeriatrics to be hired as soon as possible. Additional 10 staff members to be hired by fiscal year 2001/2002.</p>   |
| 9. Co-ordinated Specialized Diagnosis and Support | <p>Review of specialized geriatric services, including Regional Geriatric Programs, is under way, involving Ministry of Health and Long-Term Care, Ontario Seniors' Secretariat and relevant stakeholders.</p> <p>Over the fall of 1999, experts will be called together to design specialized support networks and to develop local referral protocols. The Ontario Seniors' Secretariat has seconded staff with field experience to support this work.</p> |
| 10. Inter-generational Volunteer Initiative       | Design of program and development work with the ASO, community partners and respective student groups to begin in the fall of 1999 with implementation during the 1999/2000 school year.   |