

# **Alzheimer Strategy**

## **Next Steps to Shape the Future: A Model for Transition**

April, 2004

On March 31<sup>st</sup>, Ontario's Alzheimer Strategy came to the end of its comprehensive and ambitious five-year mandate. The Strategy has without doubt been a success. Some of the achievements include:

- Over 3,000 health care providers have received education to help them provide better care for people with Alzheimer Disease and related dementias (ADRD);
- Well over 100,000 people have received information from Public Education Coordinators;
- 90 new positions were created to promote and support services for people with ADRD;
- 36 Dementia Networks are now active; and
- Research was completed on dementia caregivers' needs.

The accomplishments of the Alzheimer Strategy have improved the quality of life in communities across the province by improving service and making life more meaningful for people experiencing Alzheimer Disease and related dementias. However, due to the Strategy's complexity and the extent of the multi-stakeholder involvement, it has not been possible to achieve its full potential in the five years.

Ontario's Strategy was unique in Canada. Many of the other provinces have adopted Ontario's lead and are in various stages of implementing their own Strategies, often building on the work pioneered in Ontario. There is even talk of a national Alzheimer Strategy. As Ontario plans for the next steps to maximize the results of its investment in the Strategy, it has the opportunity to continue to lead the way.

Over the next one to two years, additional support is needed to allow the Strategy's components to be supported and integrated to achieve maturity and be woven into the broader health and social services system.

The commitment by the government to provide permanent base funding to several of the initiatives was an important first step to integrate the achievements of the Strategy into the broader system on an ongoing basis. Specifically, these initiatives are the 40 public education co-ordinator positions, the 50 psychogeriatric resource consultant positions and the expanded respite services for people with dementia.

To achieve the full potential of the Strategy, support and co-ordination is required for:

- Two initiatives to provide strategic direction, oversight and co-ordination - an Alzheimer Council and a Roundtable; and
- Two operational initiatives - an Alzheimer Knowledge Exchange and local dementia networks.

These are described more fully below, as are two mechanisms for consultation with the community of interest to inform the detailed planning for the four aforementioned initiatives.

## CONSULTATION WITH COMMUNITY OF INTEREST

In early April 2004 two formal consultations will be held to better inform the next steps to maximize the return on the investments of the Alzheimer Strategy with the goal of making life more meaningful for people experiencing Alzheimer Disease and related dementias. A broad range of stakeholders and content experts have been invited to participate in these structured consultations. The consultations have been designed to produce:

- A broader and deeper base of understanding of the achievements and lessons learned from the implementation of the Strategy;
- Recommendations for action; and
- The creation of an inventory of resources and potential partners (individuals and organizations) that can form the foundation from which to undertake the recommended actions.

### **Think Tank**

A one-day Think Tank has been scheduled for April 8, 2004 to kick start the implementation of the Roundtable. Approximately 75 participants will bring diverse and innovative perspectives to inform the creation of the Roundtable. The participants represent people affected by dementia, a broad array of service providers reflecting all aspects of community life, academics, planners and policy makers.

A preliminary report will be provided to the April 16th and 17<sup>th</sup> Alzheimer Strategy Workshop participants.

A final report will be presented to the Ontario Seniors' Secretariat to inform the creation of a Roundtable with a mandate to develop a framework for planning for persons with dementia and their family and caregivers within a context of healthy aging. The report will also inform the work of the Alzheimer Council and the development and work of the Alzheimer Knowledge Exchange.

### **Alzheimer Strategy Workshop**

This two-day invitational workshop, April 16 and 17, 2004, is designed to reflect on what has been accomplished through the Strategy and, through use of an open space approach, create a shared commitment and an action plan to maximize the return on the investments of the Alzheimer Strategy. Approximately 120 participants will bring their unique knowledge of the achievements and lessons learned from the implementation of the Strategy to date and contribute to planning for a future that sustains and builds on the achievements of the Strategy and better integrates them into the broader health care system.

The Interim Alzheimer Council will consolidate the Workshop's recommendations, initiate preliminary actions and reinforce the commitment of the participants to contribute to the achievement of the actions.

The implementation of the action plan arising from the Workshop will occur over the next four to eighteen months, depending on the actions identified. The Alzheimer Council and the Roundtable, as appropriate, will assume responsibility for prioritizing, co-ordinating and

supporting the actions arising from the Workshop. The Alzheimer Knowledge Exchange (AKE) can serve as a forum to distribute information from the Workshop and link and co-ordinate the action groups created. Actions identified at the Workshop may inform the development of the AKE.

## **STRATEGIC DIRECTION, OVERSIGHT AND CO-ORDINATION**

Two time-limited committees are required to provide strategic direction, oversight and co-ordination – the Alzheimer Council and the Roundtable. Both should be established in the early fall of 2004. Two types of support are required to implement these initiatives.

- Financial support to launch the Alzheimer Council is being sought from government, including meeting expenses, travel, and a part time co-ordinator. A budget will be submitted shortly.
- A continued partnership between government and community stakeholders in the form of appropriate representation on the Alzheimer Council and Roundtable

### **Alzheimer Council**

A new committee consisting of key community and government representatives with the purpose of co-ordinating and overseeing the systemic changes and impacts arising from the achievements of the Alzheimer Strategy, and to retain the focus on improving service and making life more meaningful for those experiencing Alzheimer Disease and related dementias. Its specific mandate will be to:

- Ensure that the focus of the elements of the Strategy remains on improving service and making life more meaningful for those experiencing Alzheimer Disease and related dementias;
- Provide support, co-ordination and overall direction to the components of the Strategy that are continuing forward;
- Promote systemic change to support the needs of the rapidly growing population affected by Alzheimer Disease and related dementias;
- Foster and support linkages between consumers, providers, organizations, and policy makers; and
- Identify opportunities and models for future development of services, education, research and support of public policy.

The committee will be in place in September 2004 and is expected to have a mandate extending approximately two years. An interim committee is in place and will oversee the development of the permanent committee. The interim committee will develop the action plan from the recommendations arising from the Workshop and reinforce the commitment of the Workshop participants to contributing to the achievement of the actions.

Membership will be representative of the continuum of care, including people who depend on the services, people and organizations that provide the services and those who influence service (policy makers, educators, researchers). Membership will include people affected by dementia and their care partners. Input from the Think Tank and Workshop will assist with the

identification of the permanent membership for the Alzheimer Council and the completion of the mandate.

There will be cross representation with the Roundtable and active two-way links to the Alzheimer Knowledge Exchange.

### **Roundtable**

This new committee that is a partnership of stakeholders and government will be led by the Ontario Seniors' Secretariat. The purpose of the Roundtable is to develop a framework that will serve as a tool for the public sector, broader public sector and the private sector in planning for persons with dementia and their caregivers within a context of healthy aging and to make recommendations for implementing the framework. The Roundtable will also foster an environment of collaboration with a view to promote public awareness of dementia and its relationship to healthy aging. The Think Tank will provide advice on the mandate and work plan for the Roundtable.

The Roundtable will have a broad-based membership. Members will be selected using a population health focus, and to ensure participation of consumers, planners and policy-makers, researchers and academics and service providers (e.g., health care providers and non-health care service providers utilized by people affected by Alzheimer Disease and related dementias and seniors in the community). There will be cross representation with the Alzheimer Council. The Think Tank, scheduled for April 8, 2004, will provide advice on criteria to select the best possible membership for the Roundtable.

It is contemplated that the Roundtable will be initiated in the early fall of 2004, with a term of operation of approximately one year.

The Roundtable and the Alzheimer Knowledge Exchange (AKE) will be linked and will exchange information. The Roundtable also will receive information from all ongoing projects that had their origins in the Alzheimer Strategy.

## **OPERATIONAL INITIATIVES**

### **Alzheimer Knowledge Exchange**

Alzheimer Knowledge Exchange (AKE) is in the development stage. It will be an active means of co-ordination and support to link people, ideas and resources, and a vehicle to provide support and co-ordination to mature (sustain, advance and integrate) the Strategy initiatives in order to maximize the Alzheimer Strategy investment. The Alzheimer Knowledge Exchange (AKE) will build on the successes of the Strategy and using the input from surveys and consultations over the past year. It will provide useable information to local communities and change champions and collect relevant new knowledge and practice.

The proposed AKE consists of:

- A clearinghouse / resource centre (Alzheimer Resource Centre)
- An interactive exchange

- Moving innovations in practice forward.
- Support for “change champions” and end users
  - o “Change champions” are people who are acknowledged as leaders in changing the way service is provided and improving co-ordination and links across components of the system in their community or organization. They are service providers whose role was developed through the Strategy (e.g., Psychogeriatric Resource Consultants, Public Education Co-ordinators, P.I.E.C.E.S. and U-FIRST trained staff, physician Opinion Leaders and Peer Presenters, and Advance Care Planning Resource Team members).
  - o “End users” are people with ADRD, their families and caregivers, service providers and the broader community of interest that have a specific interest or connection with ADRD.

A proposal has been submitted to the MOHLTC and OSS for the implementation of the first phase of the AKE. Phase 1 (start up) should be implemented starting in the summer of 2004 and will consist of:

- Establishment of the basic infrastructure, including an AKE Steering Committee and a Project Development Co-ordinator;
- Development and initiating implementation of the plan for the Internet based component of the AKE, including transition to the AKE website of the web-based forums established during the Alzheimer Strategy or links to them;
- Design and initiating implementation of the Alzheimer Resource Centre (ARC), including the clearinghouse function for references and educational programs;
- Development of educational resources, including support for and links to the curriculums, educational tools and resources developed or initiated through the Alzheimer Strategy, in order to:
  - o Keep the curriculums, tools and resources current;
  - o Promote consistent use of language, core learning goals and current information;
  - o Make the curriculums, tools and resources accessible to all change champions; and
- Complete an assessment of knowledge exchange needs using a subgroup of the change champions targeted by the AKE; and
- Stakeholder engagement and promotion of AKE.

Later phases will be scheduled once the first phase is underway.

The AKE will provide the critical function of maintaining and disseminating knowledge generated through the initiatives of the Alzheimer Strategy, e.g. curricula, expert advice repositories, best practices, etc. The AKE will support the change champions created through the Strategy and will co-ordinate and be linked to the physician education website created under the Strategy.

There will be a link to the Alzheimer Council through representation on the AKE Steering Committee and the Council will provide guidance on the priorities and approach of the AKE.

Information and resources from the AKE will inform and support the work of the Council and the Roundtable.

Support, in the form of active participation by key community stakeholders will be an integral part of this initiative.

### **Dementia Networks**

Local dementia networks were promoted and supported through the Alzheimer Strategy; however, the networks are responsible to and operated by their local community. Dementia networks bring together people and organizations that have a role in making life more meaningful for people with Alzheimer Disease and related dementias, their families and caregivers. Dementia Networks vary in structure and mandate depending on their level of maturity and the needs of the local community. Some networks have a mandate that is broader than Alzheimer Disease or related dementias, i.e. Specialized Geriatric Services, Seniors Mental Health, etc. Some networks have been in existence for a number of years and others are in an early stage of development.

The dementia networks provide an essential co-ordinating, developmental and supportive function at the local level for services arising from the Strategy, e.g. information on educational opportunities, linking and co-ordinating the work of the Change Champions, etc. The networks also link the Strategy related services into the broader health and social services system and will provide a two-way link between the “grassroots” and the Alzheimer Council and Roundtable. The Alzheimer Knowledge Exchange will be a source for current information required by the local networks and serve as a hub to link the networks across the province.

The 50 Psychogeriatric Resource Consultant positions, created through the Strategy have, as part of their mandate, a responsibility to support the work of the local dementia network(s). The 40 Public Education Co-ordinator positions created through the Strategy also provide support to the local network(s).

If the local networks are to attain their full potential, a co-ordinating and supportive process will be required for at least 18 more months. This co-ordination process will facilitate the sharing of best practices and lessons learned across the local networks. The Alzheimer Council will provide co-ordination and linkage on a provincial basis. When fully operational, the Alzheimer Knowledge Exchange it is intended to take on the role of co-ordinating and supporting the networks on an operational level.