

# A GUIDE TO DEVELOPING A DEMENTIA NETWORK

Submitted By: Dementia Networks Work Group as part of Ontario's Strategy for Alzheimer Disease and Related Dementias on January 21, 2002

## **A WORK IN DEVELOPMENT**

This Resource Guide will be made available to existing dementia networks and developing networks to field test and to gain further insights into network development, challenges, opportunities, and strategies for success that will be incorporated into the Guide by the Dementia Networks Work Group periodically for the duration of Ontario's Strategy for Alzheimer Disease and Related Dementias.

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# A GUIDE TO DEVELOPING A DEMENTIA NETWORK

## EXECUTIVE SUMMARY

This Resource Guide is a product of Ontario's Strategy for Alzheimer Disease and Related Dementias. As part of the Strategy, Initiative #9 – Coordinated Specialized Diagnosis includes the design of local, specialized support networks to support persons with dementia, their families and caregivers.

This Guide will be made available to existing dementia networks and developing networks to field test and to gain further insights into network development, challenges, opportunities, and strategies for success that will be incorporated into the Guide by the Dementia Networks Work Group periodically for the duration of Ontario's Strategy for Alzheimer Disease and Related Dementias.

### Goal of Dementia Networks

The goal of dementia networks is to improve the system of care required by persons with dementia, their families and caregivers. This includes **all** service providers and organizations that enhance the well-being of persons with dementia, their families and caregivers.

### Purpose of Dementia Networks

The purpose of dementia networks is to serve as a vehicle to facilitate people and resources coming together locally, regionally and provincially to improve the system of care (including service delivery, education and research) for persons with dementia, their families and caregivers. Dementia networks formalize, improve and build on existing relationships/linkages and provide a means to achieve what autonomous organizations cannot do on their own.

### Benefits of Dementia Networks

1. *Persons with dementia* – benefit from improved access and more timely and appropriate services, information and support.

2. *Families and caregivers* – benefit from better access to information and support.
3. *Providers* – benefit by being able to do their job better and more efficiently.
4. *Health system* – benefits by sharing expertise and using resources better.
5. *Overall* – networks serve as a forum for system-wide planning and problem solving.

## **Dementia Networks do not**

1. Integrate all services under one management and funding structure.
2. Provide direct services.

## **How do they work?**

Networks rely on:

- A willingness and the ability of members to work together towards common goals in order to improve the system of care for persons with dementia, their families and caregivers.
- Some level of organization and in kind contribution from members.
- The use of influence, persuasion, consensus building and information sharing to improve and build on existing linkages between organizations.

## **How do Dementia Networks relate to other networks?**

It is important that dementia networks identify and build on existing relationships/linkages with other related networks in the community in order to improve the system of care for persons with dementia, their families and caregivers.

## **Why develop Dementia Networks now?**

The creation or enhancement of existing dementia networks will provide a vehicle to share information concerning new developments and opportunities

in health care to improve the system of care for persons with dementia, their families and caregivers.

This Guide provides an opportunity for existing or developing dementia networks to provide feedback concerning local network development, that can be shared with other existing or developing dementia networks across the Province. The Dementia Networks Work Group will update this Guide as feedback is received from existing or developing dementia networks.

## **Highlights of the Guide**

This Guide offers practical information to assist communities in establishing a dementia network or for existing networks that are looking for a resource to enhance the functioning of their network. A description of what a dementia network is and how a dementia network can improve the provision of care to persons with dementia, their families and caregivers is included.

This resource guide is not a recipe for the creation of a dementia network; it offers strategies to assist communities in the planning and creation of a dementia network. The material is broad enough to allow communities the opportunity to develop a dementia network that is reflective of their community needs. The goal is to improve the system of care required by persons with dementia, their families and caregivers.

## SECTION 1 – ABOUT THIS GUIDE

This resource guide is for use by all people concerned about service delivery, education, research and planning associated with Alzheimer Disease or related dementias. This guide has been written to help communities develop their own “home grown” dementia network.

**Local dementia networks bring together the right combination of players to work together towards an approach that is centred on persons with dementia, their families and caregivers over time and across settings.**

This guide explains what health networks are, what a dementia network can do for your community and offers practical advice on how to go about developing one. It seeks to balance the ideal and the practical, realizing that there will be differences in how goals are pursued in each community. Resource information from health networks in Ontario and elsewhere document successes, lessons learned, and barriers overcome. This Guide is relevant to both rural communities and urban centres.

Local communities can use this resource guide to develop a dementia network that is reflective of their own circumstances or to modify and build on an existing network.

This resource guide does not need to be read in its entirety. It can be used as a reference or as a basis for discussion. This guide cannot anticipate or address all circumstances that might be encountered. Some aspects may be more relevant in some communities than in others. This resource guide gives a common vocabulary and framework within which to start or to enhance an existing network. Communities will undoubtedly depart from and go beyond the contents of this guide.

In areas designated under the *French Language Services Act (FLSA)*, the planning, the coordination and the delivery of services must be consistent with the provisions of the Act.<sup>1</sup>

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<sup>1</sup> Please see Office of Francophone Affairs, Ontario Government web site for a map and list of the 23 designated areas in the province. The web site is:  
<http://www.ofa.gov.on.ca/english/23region.htm#content>



## SECTION 2 – BACKGROUND

### 2.1 Introduction

This resource guide is a product of Ontario's Strategy for Alzheimer Disease and Related Dementias.<sup>2</sup> The Ontario Seniors' Secretariat and the Ministry of Health and Long-Term Care announced this comprehensive multi-faceted strategy in September 1999.

This Guide has been created through the voluntary and collaborative effort of many persons across Ontario, most notably the Dementia Network Work Group, seventeen persons from a cross section of communities, professions, and cultural backgrounds, united by their involvement in some aspect of dementia care. These individuals were invited by the Ontario government to come together to develop a resource guide for use by local communities to assist them in creating a local dementia network. Four regional consultations took place in June 2000 to assist in the development of a practical resource guide. The Work Group was also mandated to provide recommendations in the ongoing development and guidance of dementia networks in Ontario. Their work has been greatly enriched by the ongoing research into four Ontario dementia networks.<sup>3</sup>

### 2.2 Ontario Alzheimer Strategy

The Ontario government announced its Strategy for Alzheimer Disease and Related Dementias in September 1999, the first comprehensive, multi-faceted provincial strategy on Alzheimer Disease to be introduced in Canada.

The government is investing \$68.4 million over five years on a 10-point action plan to improve the quality of life for persons with Alzheimer Disease and related dementias and to provide support to their caregivers and families. The Strategy is comprised of ten separate but related initiatives. The 10 initiatives are:

1. Staff Education and Training
2. Physician Training
3. Public Awareness, Information and Education
4. Planning for Appropriate, Safe and Secure Environments

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<sup>2</sup> For further information concerning Ontario's Strategy for Alzheimer Disease and Related Dementias please visit the Ontario Seniors' Secretariat web site at <http://www.gov.on.ca/mczcr/seniors/english/alzheimer-strategy.htm>

<sup>3</sup> There is a Dementia Care Network's Study involving the networks in Hamilton, Niagara, Ottawa and Toronto underway with a completion date in 2002. This is a two-year study and a collaborative project led by the University of Toronto and McMaster University with involvement of University of Ottawa and Queen's. The study is funded by the Canadian Health Services Research Foundation and the Ontario Ministry of Health and Long-Term Care. The co-principal investigators are Dr. Louise Lemieux-Charles, University of Toronto and Dr. Larry Chambers, McMaster University.

5. Respite Services for Caregivers
6. Research on Caregiver Needs
7. Advance Directives on Care Choices
8. Psychogeriatric Consulting Resources
9. Coordinated Specialized Diagnosis and Support
10. Intergenerational Volunteer Initiative

An Advisory Committee, comprising citizens active in the field of dementia from across Ontario has provided advice and guidance to the government on the implementation of the ten initiatives and meets to ensure coordination across the 10 initiatives at the regional level.

Initiative #9, “Coordinated Specialized Diagnosis and Support,” has three components which include: the design of local, specialized support networks to support persons with dementia, their families and caregivers through the front line agencies that support them; the creation of a research coalition to plan and monitor Alzheimer research; and a review of specialized geriatric services to refine their scope and mandate to make their expertise more readily available to persons with Alzheimer Disease and their families. This Guide has been developed in response to the first component of this Initiative. The design of local, specialized support networks stems from a belief that improving dementia care is not only a matter of specific service enhancements and educational initiatives, but that services need to be tied together at another level through collaborative and client-focused dementia networks if they are to be easily accessible, timely and appropriate.

### **2.3 What is dementia?**

Dementia is a group of symptoms that affects the brain. It involves a decline in memory, changes in thinking, perceiving and acting. Dementia interferes with an individual’s daily functioning and is commonly accompanied by changes in personality, mood and behaviour. People of any age can develop dementia, although it is much more common in older people.

There are many kinds of dementia. The most common causes are Alzheimer Disease and vascular dementia.<sup>4</sup>

<p><b>The effects of dementia are gradual.</b> <b>Dementia affects the brain.</b> <b>Dementia is a progressive illness.</b></p>
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<sup>4</sup> The Alzheimer Society of Ontario is able to provide further information concerning Alzheimer Disease. Information is available at: <http://www.alzheimer.ca>

## Alzheimer Disease:

- accounts for roughly two-thirds of all dementias;
- is a progressive disease of the brain, in which there is a gradual loss of function;
- affects cognitive functions such as thinking, memory, and judgement;
- affects a person's behaviour, mood, emotion, language ability and ability to complete such seemingly simple activities of daily living as brushing their teeth or combing their hair;
- gradually destroys vital nerve cells in the brain;
- affects each person differently.

Although new drug treatments are showing promise in slowing down the decline, there is no known cause or cure, and Alzheimer Disease is ultimately fatal.<sup>5</sup>

In the vascular dementias, there are problems with the blood supply to brain cells. For example, the most common type of vascular dementia is multi-infarct dementia. Tiny strokes (infarcts) damage small areas of the brain. Each small stroke contributes to the progression of dementia.

Other causes of dementia may include dementia of the Lewy Body Type, Parkinson's Disease, Pick's Disease and Huntington's Disease. All forms of dementia seriously affect an individual and require a great deal of attention; local networks should not be restricted to Alzheimer Disease alone.

## 2.4 What is a health network?

**A health network is a vehicle to share information and is committed to the achievement of common goals, advocacy and promoting linkages. It provides a means to achieve what individual organizations cannot do on their own. Member agencies still function independently outside of the network, but with greater awareness and improved interfaces with other agencies, programs and services provided in the community. Health networks can be provincial, regional or local.**

In recent years, the delivery of health care services has changed greatly. The challenges facing all health service providers are increasingly complex and require innovative, collaborative and comprehensive efforts to continue to improve Ontario's health care system. **Health service networks facilitate the coordination of services by bringing together a variety of providers, educators, researchers, consumers and other relevant stakeholders to problem solve, exchange information and focus on the needs of persons with dementia, their families and caregivers beyond the single service**

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<sup>5</sup> For information concerning the Canadian Medical Association Dementia Guidelines, June 1999 from the Canadian Consensus Conference on Dementia see: <http://cma.ca/cmaj/vol-160/issue-12/dementia/index.htm>

**provider. The intent of a health network is to improve service linkages and access through the continuum of client care.**

A local health network can be described as a community-led partnership among at least three health care provider organizations intended to improve access to needed health services and to make it easier for persons to use the health care system.<sup>6</sup>

Although they may vary widely in scope and structure, successful health networks are:

- **Based on community needs** – Services are linked and systems are developed on the basis of community needs.
- **Focused on the client** – Improved care available to persons with dementia, their families and caregivers is the focus and goal.
- **Supported by innovative and enterprising leadership**- Change champions are leaders.
- **Supported by key local stakeholders**- Essential to include community members and persons with dementia, their families and caregivers.
- **Based on a willingness to partner**- Members are prepared to collaborate on an ongoing basis.
- **Focused on service and system change**- Members are willing to change how they do business.
- **Based on representation across a continuum of care** - Involvement of individuals, organizations and agencies in all relevant health sectors and systems, e.g., persons with dementia, acute care, specialized geriatric, medical and psychiatric care, long-term care, complex continuing care and community care.
- **Based on representation across professional groups**- Individuals and organizations that provide knowledge, expertise and resources across service, education, research, and planning.<sup>7</sup>

Health Networks are **NOT**:

- **Corporations** integrating all related health services under a single governance, management and funding structure.
- **Direct providers** of services to clients, except where specifically legislated, e.g., Cancer Care Ontario is a direct service provider. Individual organizations remain responsible for providing direct services to clients.
- **All about computers**, but are mainly about people who may be working in isolation having the opportunity to share their knowledge. Computers and information systems do play an important role, however, in providing the kind of information upon which informed decisions can be made.

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<sup>6</sup> The Toronto District Health Council submitted a report to the Health Services Restructuring Commission, December 1999, entitled “Integration In Action: Lessons Learned From Networks In Toronto”. This report provides a review of seven networks in Toronto.

<sup>7</sup> Adopted from the Ontario Hospital Association. (1998). *Health Networks, Seven Case Studies: A Description and preliminary analysis*.

## **2.5 Purpose of a Dementia Network**

The purpose of dementia networks is to serve as a vehicle to facilitate people and resources coming together locally, regionally and provincially to improve the system of care (including service delivery, education, research and planning) for persons with dementia, their families and caregivers. Dementia networks formalize, improve and build on existing relationships/linkages and provide a means to achieve what autonomous organizations cannot do on their own.

Networks are involved in dementia care because of their interest in improving the system of service delivery, education, research and planning in the area of dementia.

At the core of a Network must be:

- The understanding that each community has strengths and resources upon which to build.
- A respect for the importance of client centred planning and service delivery.

The Network can engage the community in consultations to determine the needs, concerns, and strategies that best address care for persons with dementia, their families and caregivers.

The complexity and progressive nature of dementia has implications for networks. They are:

- Improved linkages between service organizations are necessary as persons with dementia, their families and caregivers require an array of different services at different times across sectors.
- Improved linkages between service organizations are required as the illness is progressive and requires a continuity of care and accessibility of different services at different times according to the changing needs of persons with dementia, their families and caregivers.
- Improved linkages between service organizations are required as the illness often causes interdependent changes in physical, intellectual and emotional functions of the person and the support of physical and social environments.
- Greater knowledge, skills, coordination and access to individuals in organizations who have the ability to address issues across the physical, intellectual, emotional, functional, environmental and social domains are needed.

## **2.6 Why develop a network now?**

The creation or enhancement of existing dementia networks will provide a vehicle to share information concerning new developments and opportunities

in health care to improve the system of care for persons with dementia, their families and caregivers.

## **2.7 How do other networks relate to the dementia network?**

It is important that dementia networks identify and build on existing relationships/linkages with other related networks in the community in order to improve the system of care for persons with dementia, their families and caregivers.

## **2.8 Ministry involvement**

Both District Health Councils (DHC) and Ministry of Health and Long-Term Care (MOHLTC) regional offices can provide a valuable support and integrative function to and across several networks. Networks can also act as a resource to DHCs and MOHLTC offices as they relate to their activities and functions associated with the care of persons with dementia, their families and caregivers.

### Ministry of Health and Long-Term Care Regional Offices

The (MOHLTC) has been decentralizing -- adding hospital care and mental health services to the already decentralized long-term care functions. This integration of health care functions to the regional level makes access to government easier and more responsive to local situations. The regional office is a valuable source of practical help in network development.

The MOHLTC regional offices can be helpful to local networks in facilitating, consulting and supporting networks. This includes assistance in fostering among others, access to specialized services.

## **2.9 District Health Councils**

The DHC can lend their facilitation and coordination expertise to help start or strengthen a local network. A DHC can provide assistance to a local dementia network in some of the following areas: assessing need; developing an inventory of services; assessing gaps; fostering partnerships; planning; providing meeting space; facilitating meetings; and helping with the development of protocols, service agreements and evaluation.

A DHC could be involved in several local dementia networks and can be a vehicle for communication across adjacent networks.

## SECTION 3 – GETTING STARTED

### 3.1 Target population

- a) Persons with dementia, their families and caregivers;
- b) Service providers, health care professionals, agencies and organizations that provide care and support to persons with dementia, their families and caregivers;
- c) Researchers, educators, planners and advocates who seek improved dementia care within their community.

### 3.2 Membership

#### (i) Form working group of local champions

It is always a judgement call to decide how to tradeoff the efficiencies of a small group versus the inclusiveness of a larger group. Each community will need to assess what works best for them.

Generally, if no network activity has occurred related to the service needs of persons with dementia, their families and caregivers it may be wise for a few committed and credible community leaders to do some background work before convening a larger group to decide how to proceed. This will provide an opportunity for some thought to the various options available, which could then be put to a larger group for discussion.

#### (ii) Key service organizations and providers

This will vary from community to community but will likely include the following health, social service and information agencies:

- Alzheimer Society chapter;
- Community Care Access Centres (CCAC's)
- Primary care physicians, Medical Directors of long-term care facilities and CCAC's and opinion leaders identified by the Ontario College of Family Physicians;
- Specialized geriatric services<sup>8</sup>;
- Specialized services<sup>9</sup>;
- Advance care planning resource team members;
- Adult day programs;
- Community psychiatric and mental health services;
- Community health and social service agencies;
- Hospitals, including emergency departments;

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<sup>8</sup> Examples of specialized services for seniors include geriatric medicine and geriatric psychiatry services.

<sup>9</sup> Examples of specialized services include neurology, internists, orthopedists, and ophthalmologists among others.

- Complex continuing care facilities;
- Long-term care facilities;
- Public health;
- Police;
- Education and research organizations, e.g., colleges and universities.

The Public Education Coordinator from the local Alzheimer Society Chapter and the Psychogeriatric Resource Consultants may be able to assist in identifying who should be involved.

It is important to recognize that persons with dementia have both long-term care and mental health needs and both sectors need to be involved. As well, persons with dementia are prone to all the medical, psychiatric and functional problems that affect the general population. Any local dementia network should make sure that it involves organizations/individuals with expertise to address the broad physical, intellectual, emotional and functional health of the individual with dementia as well as their families and caregivers.

The involvement of administrative leaders from the above organizations can be an important source of support and can enhance the knowledge of front-line service providers by assisting with the development and implementation of a dementia network in the local community.

### **(iii) Key stakeholders**

They represent not only the service providers, but also researchers, planning bodies and persons affected by dementia that come together to address a specific issue. Initially, you may have a small membership base, with persons having specific vested interests. As the network evolves, representation may increase at the work group level and often on the steering committee.

In addition, the Dementia Networks may explore linkages with other networks and planning organizations including the District Health Councils and District Mental Health Implementation Task Forces.

Although most health networks are oriented around a spectrum of health and social service providers, there is a strong argument for including the individuals for whom the network is being established. In the case of dementia, this means persons with dementia, their families and caregivers who can represent the needs of those with dementia.

### **(iv) Key supporters, enablers**

The Psychogeriatric Resource Consultants as well as the Public Education Coordinators through the local Alzheimer Society chapters have a supportive and facilitative role in existing networks and in the development of dementia networks where none exist.<sup>10</sup>

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<sup>10</sup> The Public Education Coordinators and Psychogeriatric Resource Consultants should not be assumed to represent their organization in the network.



The Public Education Coordinators through the local Alzheimer Society chapters work with local organizations and networks to develop and facilitate support for persons with dementia, their families and caregivers to ensure that public awareness and education is facilitated across the province.

A key function of the Psychogeriatric Resource Consultants is to assist in developing and maintaining local agency networks. The Psychogeriatric Resource Consultants will be a resource for existing networks. Facilitating and maintaining existing local networks is consistent with their mandate.

PIECES trained staff in long-term care facilities and at CCACs are also key individuals who should be involved in discussions concerning the development of a local dementia network.

#### **(v) Potential leaders**

The identification of a capable and credible leader who is willing to devote time to the creation of a dementia network will assist in the development of an effective health network. **It is essential not to confuse leadership with ownership.** Although one or two champions may take the lead, it should be emphasized that each network member has an **equal** stake in the network.

If there is a primary care physician in the community with a special interest in dementia and who is a respected opinion leader, their involvement should be encouraged. Primary care physicians are an important group to attract as they are usually involved in providing care to persons affected by dementia throughout the course of the dementia. The Ontario College of Family Physicians may be able to identify physicians who are opinion leaders in their community.<sup>11</sup>

### **3.3 Determine your catchment area**

Each community will have to determine this based on existing boundaries and local service patterns.

Key Considerations:

- **Local dementia networks need to be LOCAL, which means that the partners must feel real interdependencies.**
- **Use of logical existing boundaries of related organizations may avoid disruptions in the continuity of care for persons with dementia, their families and caregivers.**

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<sup>11</sup> Ontario's Strategy for Alzheimer Disease and Related Dementias, Initiative #2 Physician Education includes up to 140 Physician Opinion Leaders being identified across the province.

In most areas of Ontario, the boundaries of the local Alzheimer Society chapters and the Community Care Access Centre overlap. In many situations, this area may be a logical catchment area for a local dementia network.

Other considerations:

- It is preferable for persons with dementia to receive care and services close to home. Although a critical mass of services is required to create a viable network, it is preferable to create local networks as opposed to a single network across a vast geographic region.
- Local network boundaries should be adjacent to one another and neither overlap nor leave areas uncovered. Where local networks are alongside one another, boundary relationships should be negotiated.
- Local networks should explore and implement inter-network coordination functions to ensure access to regional based resources.
- Advice may be sought from Regional Offices of MOHLTC and/or from local District Health Council on network boundaries.

### **CHECKLIST**

- Determine Membership**
- Identify Key Service Providers**
- Identify Potential Leaders**
- Determine Your Catchment Area**
- Consider Regional interfaces**

## SECTION 4 – INITIAL TASKS

### 4.1 Inventory of programs and services

The initial approach in developing an inventory of programs and services needed by persons with dementia, their families and caregivers may focus on dementia services. The long-term vision of the network should include all services used by persons with dementia, their families and caregivers.

A description, review and analysis of where persons with dementia, their families and caregivers go for services and who currently does what is a very useful exercise to show network members the scope of services that each organization provides, in addition to determining gaps and/or problem areas. This review will prove invaluable in selecting reasonable and reachable goals.

References and planning tools can be found in Appendices A, B and C.

Suggested questions include:

1. What services are needed by persons with dementia, their families and caregivers over the course of the disease?
2. What services are available in the community for persons, families and caregivers living with dementia? This analysis should include location, waiting lists, volumes, number and type of staff available.
3. Are there any gaps, duplications, and inefficiencies in service delivery? Are these due to poor links?
4. What informal alliances and formal partnerships (e.g. service agreements, shared referral and/or care protocols, etc.) currently exist among these service providers?
5. Where applicable, how are providers meeting the service needs of French speaking populations and other linguistically and ethnically diverse populations?
6. Where applicable, how are providers meeting the needs of special populations, e.g., persons with Alzheimer Disease and Down Syndrome or early-onset dementia?

Review local community to see if the following elements of care are available for persons with dementia, their families and caregivers.

Key service	Key questions
<b><i>Public awareness – pre-diagnosis</i></b>	<ul style="list-style-type: none"> <li>• Is there good public awareness of the early signs and symptoms of dementia and advantages to early identification?</li> </ul>

<p><b>Assessment</b></p>	<ul style="list-style-type: none"> <li>• Does the provision of a holistic assessment that is focused on the person's strengths, challenges and preferences exist?</li> <li>• Is there assessment available at key stages in the progression of the disease and where there has been a significant change in the person's functioning?</li> <li>• Is there provision for assessment of the family and caregivers?</li> <li>• Are assessment results for persons with dementia, their family and caregivers linked?</li> <li>• What services exist to assess the person's fitness to drive?</li> </ul>
<p><b>Diagnosis</b></p>	<ul style="list-style-type: none"> <li>• What services provide for the diagnosis of dementia, particularly Alzheimer Disease at an early stage?</li> <li>• Are there services available with specialized training and skills for complex or unusual presentations of dementia?</li> <li>• Do care providers know how to access diagnostic services?</li> </ul>
<p><b>Treatment</b></p>	<ul style="list-style-type: none"> <li>• What exists for the treatment of the whole person including medical, psychiatric and functional issues?</li> </ul>
<p><b>Care planning</b></p>	<ul style="list-style-type: none"> <li>• What services are involved in care planning that reflects the needs and strengths of persons with dementia, their families and caregivers?</li> <li>• Is there planning that is longitudinal and reflects progression of the disease?</li> <li>• Is care planning linked to assessments?</li> <li>• Is information provided concerning advance care planning?</li> <li>• Does the process for care planning address the transitions between sectors, e.g., placement to long-term care facilities from home.</li> </ul>

<p><b><i>Counseling</i></b></p>	<ul style="list-style-type: none"> <li>• What supports are available to address the psychosocial as well as the practical aspects of living with dementia or caregiving throughout the course of the disease?</li> <li>• Is grief counselling available at all stages of loss for persons with dementia, their families and caregivers?</li> </ul>
<p><b><i>Education &amp; training</i></b></p>	<ul style="list-style-type: none"> <li>• Is there specialized training and education available for persons with dementia, their families and caregivers, e.g., advance care planning and environmental safety measures?</li> <li>• Is similar education and training available for all health care providers, including physicians and volunteers?</li> </ul>
<p><b><i>Legal &amp; financial</i></b></p>	<ul style="list-style-type: none"> <li>• Is there legal assistance for persons with dementia, their families and caregivers at all stages of the dementia?</li> <li>• Is professional financial advice available?</li> </ul>
<p><b><i>Activation services</i></b></p>	<ul style="list-style-type: none"> <li>• What programs and activities provided by staff and volunteers in a variety of settings are available to accommodate the needs of all persons with dementia?</li> <li>• What social programs are available for families and caregivers?</li> </ul>
<p><b><i>Safety</i></b></p>	<ul style="list-style-type: none"> <li>• What services provide home safety assessments?</li> <li>• What services are available to assist a person who is in danger of wandering, e.g., Alzheimer Society wandering registry and police search and rescue?</li> </ul>
<p><b><i>In-home services</i></b></p>	<ul style="list-style-type: none"> <li>• Is there a full continuum of services including paid in-home care?</li> <li>• Do appropriately trained workers provide services?</li> <li>• Is there a continuity of care providers?</li> <li>• Are these services available regardless of the type of home situation, e.g., retirement home?</li> </ul>

<b><i>Respite care</i></b>	<ul style="list-style-type: none"> <li>• Are there services that provide for regular breaks each week and planned vacation care?</li> <li>• Is there a full continuum of respite services including paid in-home care?</li> </ul>
<b><i>Transportation</i></b>	<ul style="list-style-type: none"> <li>• Do services exist to transfer persons with dementia, their families and caregivers to medical and social programs?</li> </ul>
<b><i>Case management</i></b>	<ul style="list-style-type: none"> <li>• Is there assistance with navigating the transitions that characterize the dementia care journey?</li> <li>• What services provide a personalized and consistent source of information and guidance?</li> </ul>
<b><i>Crisis care</i></b>	<ul style="list-style-type: none"> <li>• What services provide for emergency medical and respite care?</li> </ul>

## **4.2 Focus Groups**

The purpose of focus groups is to enrich the information gathered by engaging targeted groups/populations in discussion. The involvement of potential community partners in the process gives them a stake in the outcome. Focus groups allow for the opportunity to explore challenges, concerns and perceptions from various stakeholder viewpoints. An important task includes the above review of the elements of dementia care provided in their local community

Focus groups are best with 8-10 people, using open-ended questions to evoke discussion, provide information and explore perceptions of the community. A network member may choose to facilitate the group and record the feedback. The group sessions may typically last for 1-2 hours.

The location, transportation and time of meetings need careful consideration, e.g., caregivers may need care for the person they are caring for in order to attend. Where applicable, opportunities for focus groups to be conducted in French or languages of population served in the local community should be made available. The District Health Council may be able to assist the network in planning and holding the focus groups.

### **Suggested participants**

Include groups of individuals from whom you can learn, for example:

- Persons with dementia;
- Families and caregivers;
- Service providers, including physicians;
- Educators, researchers and planners.

As dementia is progressive, it is important to involve people who have experience at all stages of dementia.

### **Suggested questions**

Some of the questions that need to be asked to complete the picture of your community throughout **all** stages of dementia include:

- What programs are available?
- What are your concerns?
- What works?
- Where do you refer individuals?
- Where are the gaps in service?
- What are the barriers?
- What programs are available in French or alternative languages, where applicable?
- What programs are culturally sensitive/appropriate?

### **4.3 Key Informant Interviews**

The purpose of the key informant interview is to explore in depth the process for service delivery, challenges and concerns.

Key service providers/organizations are asked about programs, referral patterns and process, utilization statistics, waiting lists, barriers to service, challenges, recommendations and commitment to involvement. These can be individual or group interviews, but should be structured so that responses can be summarized and compared.

Sources for informant interviews may include:

- Alzheimer Society chapters
- Community services
- Hospitals, including emergency services
- Specialized geriatric services
- Specialized services
- Psychogeriatric Resource Consultants
- Mental health services
- Long-term care facilities
- Retirement homes/supportive housing
- Persons with dementia, their families and caregivers
- Caregiver/family support groups
- Researchers and planning councils
- Local police
- Religious leaders
- DHC French Language Services Committees

## **4.4 Mapping**

Mapping is a method used to address the elements identified for a specific concern or issue. A visual “map” of systems, programs or services can be a powerful planning tool. By determining the elements that are considered essential to an effective community response to the issue, one can determine the current situation and the perceived neglected areas. This process allows the network to focus resources and energy on the gaps or overlooked areas.

In defining needs it is important to consider the needs from a system perspective for caregivers and providers, not just for individual agencies.

Please see Appendix B: A Needs Based Planning Approach

## **4.5 What are the current trouble spots, gaps, needs?**

By documenting and analyzing the current system of services for persons with dementia, their families and caregivers it is possible to compare existing services to the ‘ideal’ model for the community. This can be helpful in identifying a number of trouble spots or gaps.

Needs can be broken down into several categories, such as:

1. Insufficient service:
  - A clear gap in the continuum of care accessed by persons with dementia, either throughout the catchment area or in a portion of it.
  - A lengthy waiting list for a particular service.
  - Barriers to accessibility, e.g., language and transportation.
2. Problems experienced in navigating the dementia pathway can be ascertained by reviewing the community development process and mapping carried out in the above section.

It is important to pay special attention to those transition points where there is greatest need for building linkages among service providers, e.g., pre-diagnosis, terminal stage and placement in long-term care facility.

## **4.6 Special issues**

### **(i) Rural and disperse communities**

Rural and disperse communities may find value in a document developed by the Ministry of Health and Long-Term Care in 1997 to help with the implementation of the recommendations of the Health Services Restructuring Commission (HSRC). “The Rural and Northern Health Care Framework” calls for “a fully integrated and coordinated network that provides access to a range of programs and services which put the patient first while using resources



more effectively and efficiently – the right care, in the right place, at the right time.”

## **(ii) Urban metropolis**

The population in most of Ontario’s largest centers is becoming more diverse and dementia networks need to be able to respond to and reflect that diversity. Issues of access, communication and an understanding of cultural traditions need to be taken into account in the work of dementia networks.

In a complex urban area, many agencies are making decisions that impact on service delivery. These decisions are often made with little or no consultation with others. However, these changes can impact on persons with dementia, their families and caregivers who often do not know where or how to get help.<sup>12</sup>

In a large urban areas where there is often a multiplicity of services available, it is important to get the family physicians and the specialists working together to avoid unnecessary duplication of service.

## **(iii) Francophone population and French language services**

There are about half a million Francophones in Ontario, Canada’s largest group of French-speaking people outside of Quebec. The *French Language Services Act (FLSA)* has been in effect since 1989. It guarantees an individual’s right to receive provincial government services in French in 23 designated areas in the Province of Ontario. Designated areas are those with at least 10% Francophone population, urban centers with at least 5,000 Francophones, and areas designated prior to the adoption of the *FLSA*.

Dementia networks covering designated areas need to address prompt access to quality French language services. This can be reflected in the dementia network’s mission and vision statements, objectives, procedures and resources. In particular, any inventory, research, needs assessment, evaluation data, care planning and training should incorporate indicators related to French language services. In addition, the membership and functioning of the dementia network should include the Francophone community. This would entail effective Francophone representation on the dementia network as well as meaningful consultation with the French-speaking population.

Dementia networks will need to provide for the translation of any of the documentation intended for public display or distribution. As well, it may be helpful to present opportunities for focus groups in French. Depending on numbers of Francophones, some networks may conduct meetings in both official languages or may have sub-groups that operate in French. Resources and linkages which dementia networks may wish to explore include the

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<sup>12</sup> Toronto District Health Council, “Creating Integrated Health Delivery Systems for Metropolitan Toronto, June 1996.

French Language Services Committees of District Health Councils in designated areas, local or regional French Language Services Networks, and Ministry of Health and Long-Term Care French Language Services Coordinators.

**(iv) Multi-ethnic populations**

In order to accommodate the needs of ethnically diverse populations local communities need to be sensitive to the service needs of multi-ethnic populations. The membership of the local dementia network should be representative of the various ethnic communities and include ethno-specific services. In seeking consultation from community members it is important that focus groups are held in other languages where appropriate. Dementia networks should consider whether there is a need to translate any information that is intended for the public in other languages.

**(v) Communities without specialized diagnostic and treatment resources**

Some communities will not have access to specialized geriatric and specialized services locally. Although specialized services are not needed to diagnose and care for all persons with dementia, each community does require access to specialized diagnostic and management consultation. The primary care physician in consultation with the person with dementia, their family and caregiver is in a position to assess whether a referral is needed to a specialized geriatric or specialized service to diagnose dementia or to manage the medical or psychosocial aspects of the disease.

If specialized services are not available locally, a community may establish a consulting relationship with another dementia network that has this resource. The Ontario College of Family Physicians is developing a mentoring program between family physicians who will be identified as opinion leaders and members of specialized geriatric medicine and psychiatry. These physician opinion leaders will be expected to take a lead role in their communities by assisting other physicians through formal and informal discussion on best practices in dementia care. As well, a number of the opinion leaders will be trained as peer presenters and will offer educational activities in their own region. A dementia website will be available for healthcare professionals and will offer a resource for clinical practice guidelines, educational resources and a mechanism to access community resources.<sup>13</sup>

Specialized geriatric services exist in the five urban centres housing medical schools.<sup>14</sup> These cities are:

- Hamilton
- Kingston

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<sup>13</sup> These educational strategies are part of Ontario's Strategy for Alzheimer Disease and Related Dementias , Initiative #2 Physician Education.

<sup>14</sup> Please see the Appendix C for contact information for these five urban centres with specialized geriatric services.

- London
- Ottawa
- Toronto

Each of these “health sciences centres” has a Regional Geriatric Program, geriatric psychiatry program and an array of other specialized services. There are also many specialized geriatric services located across Ontario, which are not affiliated with a health sciences centre.<sup>15</sup> These programs would also be instrumental in the development of dementia networks.

#### **(vi) Serving populations with special needs**

In developing dementia networks, members need to be sensitive to the needs of persons living with dementia who have a dual diagnosis, e.g., Alzheimer Disease and Down Syndrome, or other chronic diseases/disorders. As well, younger persons with dementia may require services that are not traditionally associated with persons with dementia, e.g., employment support. Persons living alone may require additional supports and outreach activities.<sup>16</sup>

#### **4.7 Realistic goals for the first year**

It is important to concentrate on measurable accomplishments that could not be achieved by individual members on their own. The advice of most health networks is to:

1. Start small;
2. Start where there is an opportunity to make a rapid and noticeable difference;
3. Start where there is energy and willingness to change.

While mobilizing providers to focus action on addressing the needs of those who experience the greatest inequities in access to high quality care, it is most important to achieve successes early on. It is necessary to be realistic and to undertake a project that is both important and achievable and that does not take more time, energy and resources than are available.

Some of the projects that can be taken on by local dementia networks include:

- Improve the means of identifying individuals in the early stages of dementia;
- Implement best practice guidelines for dementia care across the continuum of care;

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<sup>15</sup> Please see the Appendix C for a directory of services.

<sup>16</sup> The Alzheimer Society of Ontario can provide assistance with special needs populations. Please see: <http://www.alzheimer.ca>

- Develop and implement a means of managing care and support for persons with dementia, their families and caregivers over time and across the continuum of needed services.

#### **4.8 Community resource location**

Determine what resource information is available and where it is housed. It will also be important to negotiate a location for a 'library' of information. Where applicable, allocate sufficient time and resources for translation of documentation intended for public display or distribution.

#### **CHECKLIST**

- Initiate focus groups**
- Engage individuals and organizations across service, education, research, planning and speciality services**
- Complete analysis of community**
- Identify gaps**
- Summarize findings**
- Produce report, distributed and translated, where applicable**
- Set realistic goals for the first year**

## **SECTION 5 – MAINTAINING THE NETWORK**

### **5.1 Organization**

There is no specific structure that meets every community's needs. This should be determined by what is most appropriate for your community. It is necessary to distinguish between the membership of a dementia network and participation in its organizing body or steering committee. It may be impractical and unwieldy to have all network participants sitting on the organizing group or steering committee.

Specific projects may be able to be undertaken through work groups, with or without special project funding. An organizing body or steering committee of service, administrative, education, research and planning leaders could work closely with work groups created for specific projects. This organizing body could have the task of coordinating the work groups and keeping the membership informed and consulted on important decisions. Work group participants generally include direct service providers from member agencies and others with a specific interest or expertise in a particular issue.

Given the purpose of dementia networks is to serve as a vehicle to facilitate people and resources coming together locally, regionally and provincially to improve the system of care (including service delivery, education and research) for persons with dementia, their families and caregivers, it is important that decision-making is achieved through a spirit of collaboration and consensus building.

### **5.2 Functions**

As time goes on, a local dementia network may wish to become increasingly proactive and take on additional functions, such as:

- Advocacy
  - Development and dissemination of referral protocols
  - Service agreements between agencies
- New innovative projects

### **5.3 Leadership**

Responsibilities can be rotated in a way that does not make it onerous on any one person and is perceived to be equitable. The area that seems to be important is the administrative coordination of the network, i.e., keeping members informed, arranging meetings, preparing agendas, minutes, following up on action items. In some communities, one organization may take this responsibility and assign someone to spend a certain amount of dedicated time to network activities.

It is a challenge to keep members informed and appropriately involved. In addition to a high level of trust, this requires good organization and communication. Generally, small groups are more productive than large ones. A small group of people can do a lot of the background work and decisions can be brought to a larger group.

#### **5.4 Accountability**

Most newly created networks operate with an informal organizing structure in which work groups created for specific projects report back to the organizing body or steering committee. The steering committee would then have the task of assisting with the overall coordination and planning for the network. Any decisions made by the steering committee should be made in a way that is transparent and supported by the majority of members. It is essential that there is effective communication between the steering committee and all the members.

It may be helpful if the local dementia network maintains a link with the MOHLTC regional office and District Health Council for support and to enhance linkages between service providers.

#### **5.5 Responsibility**

Chances are that a few people will do most of the work in the early days. One or several local champions willing to roll up their sleeves and do much of the work is often a key to early success. As a network matures, the work can become routine and spread around more equitably. It is also possible to call on members to help out in the following ways:

- Host meetings
- Lead meetings
- Provide advice on network development
- Provide administrative support

Among the organizations that might take on some of these roles are:

- Geriatric medicine and geriatric psychiatry services
- Specialized services
- The District Health Council
- The MOHLTC regional office
- The local chapter of the Alzheimer Society
- The CCAC
- The local hospital
- Local long-term care facilities
- Community service agencies

Networks may also explore with universities and colleges, the potential of providing opportunities for co-op students to assist in its work.

## **5.6 Planning for sustainability**

### **(i) Tips for success:**

- Establish trust, especially among those not used to working together and encourage an environment where all players are recognized for their important contribution. Elicit “support in principle” at early stage, so doubters can be part of the process without committing more than they are ready to.
- Define a mission and shared vision that is focused on persons with dementia, their families and caregivers.
- Engage opinion leaders among the physicians and other service providers.
- Preserve individual agency identity/ideals while working as part of a network.
- Define a common set of services required by persons with dementia, their family and caregivers in the community. The network may want to focus on dementia-specific services at the beginning and expand to include other community services at a later stage.
- Define an organizational structure that is designed to allow members to move ahead quickly with projects.
- Engage participants and respect different types, sizes and cultures of organizations.
- Plan carefully. Planning can be slow and success is hard to see. Try to undertake at least one “quick win”.
- Assess information needs, e.g., databases and software used to develop and sustain the network.
- Continually stress the role of the network to focus on the needs of persons, families and caregivers living with dementia in the community.
- Evaluate network projects and changes to the systems of care.
- Communicate often and comprehensively.

### **(ii) Human resources**

At the early stages, it is likely that a network will require the disproportionate commitment and time of one or more local champions; this is usually not sustainable. The workload may need to be shared as a way to enhance the sense of ownership among members.

Different skills are required:

- Visionary and persuasive – This is the leader, the person(s) able to create understanding of what a local dementia network can do for persons with dementia, their families and caregivers and rally support for it. This person(s) can help the “doubters” understand the purpose of the network

and can allay fear of change. They lead without “owning.” They are consensus builders.

- Organizational – This is the person(s) who understands what kinds of organizational structures are the most efficient and effective to get the work done and keep participants informed and committed. This person often does much of the analytical and communications work.
- Administrative and secretarial – This is the person(s) who organizes meetings and prepares materials.
- Clinical and service response – This includes the experts in some aspect of dementia care who provide the content in deciding what problems need attending to and crafting the response.
- Client – Persons with dementia, their families and caregivers have an important role in informing the group of the type of care and delivery of services that would enhance their quality of life and ability to manage the consequences of dementia.
- Overall – It is important to have a broad base of skills to draw upon, including individuals with clinical, education, research and planning skills.
- Where applicable, consider knowledge and understanding of the needs of the Francophone community and other cultural communities. This is important at all levels of organization but especially where design and delivery must be appropriate from a cultural and linguistic perspective.

Without adequate support, either in-kind or funded, the work of the network may not be sustainable.

### **(iii) Financing**

Be realistic about what can be achieved through limited resources and in-kind support from participating agencies. Major projects typically require a grant from an external agency. Networks that do not have a dedicated staff person may require significant administrative in-kind support from member agencies.

#### Items to Consider

- Recognize that despite significant value of in-kind resources, there is a limit to what can be expected (this varies by network).
- Determine the types of in-kind resources valuable to the network – what resources can individuals and organizations offer, e.g., meeting space, secretarial support.
- Recognize that small agencies and individuals may not have the ability to provide in-kind support other than offering their expertise through participation at the steering committee/work group level.
- Determine if members are willing to pay dues to support the work of the network – if so, ensure the fee is manageable for all participants, e.g., prorated to agency/individual budget, and ensure the fee is not a disincentive



to participation. Recognize that participants will expect some benefit in return for dues paid.

- For a local dementia network to take on more and more activities, it may need financial resources to free up the time of persons to undertake the work. As well, there are costs associated with meetings, e.g. catering. The cost of travel and lost income can be a significant. There is also the cost of respite care for caregivers to attend.

Local provider organizations have found a variety of ways to support network activity. They include:

- Support from the global budget of one or more champion organizations. This support can come in the form of management and/or administrative time made available to coordinate network activity and supply costs.
- Providing supervision and structuring learning opportunities for a co-op university student to assist the network.
- A formal membership fee structure, usually on a sliding scale.
- Time-limited project funding from governmental or non-governmental sources, often for development of information systems.

(Local networks should confer with their MOHLTC offices to determine whether there are any restrictions on the MOHLTC-funded agencies to devote any of their funds to network activities without violating their service agreement.)

### **5.7 Is there a best model for a network?**

Many different network arrangements can be effective. Each network needs to be custom-made and adapted to local realities. The key to success is building on existing structures that have credibility and are working well. Although this will vary from community to community, most local networks are fairly similar in operational style and structure. Communities just starting out can draw on the experience of other communities with developing or mature dementia networks.

### **5.8 Examples of Dementia Networks**

- a) Hamilton: Hamilton Dementia Care Network<sup>17</sup>
- b) Niagara: Niagara Specialized Health Care for the Elderly Network<sup>18</sup>

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<sup>17</sup> Contact person is Gertrude Cetinski, Executive Director Hamilton –Halton Alzheimer Society and co-chair of the network (905) 529-7030.

- c) Ottawa: Dementia Network of Ottawa<sup>19</sup>
- d) Toronto: Dementia LINC (Local Improvement Network in the Community)<sup>20</sup>

### **CHECK LIST**

- Determine Organizational Structure**
- Clarify Leadership, Function and Responsibility**

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<sup>18</sup> Contact person is Bill Bloor, Niagara CCAC and chair of the network (905) 684-9441. The Niagara network also includes other specialized services for the elderly.

<sup>19</sup> Contact person is Barbara Schulman, Vice-President, Planning and Partnerships, SCO Health Service and co-chair of Dementia Network of Ottawa, (613) 562-6344 or [bschulma@scohs.on.ca](mailto:bschulma@scohs.on.ca)

<sup>20</sup> Contact person is Dr. Carole Cohen, Sunnybrook and Women's College Health Sciences Centre, chair of the network (416) 480-6100 ext. 4663 or [carole.cohen@swchsc.on.ca](mailto:carole.cohen@swchsc.on.ca)

## **SECTION 6 – COMMUNICATION**

### **6.1 Developing the mechanism**

There must be mechanisms established to communicate formally and informally with network participants, members of the community, agencies and health professionals. Two-way communication is essential. Organizations and individuals must be able to provide input and advice into the planning process and receive information about network plans.

An effort should be made to:

- Speak and listen to diverse opinions expressed by members.
- Share information in a timely, clear and concise manner.
- Recognize the potential for conflict and/or differences of opinion to arise around decision-making, especially when the network wishes to take an action not supported by one or more of the members.
- Ensure speed in decision making. Small obstacles may become real barriers if allowed to fester. This needs to be balanced with ensuring consensus among the majority of members.
- Share successes and lessons learned with other dementia networks, e.g., through a shared web site, publications, conferences, etc.
- Share successes and lessons learned with MOHLTC regional office and groups that influence public policy in the area of dementia.
- Consider developing written materials and/or a web site for members and the public. When planning documents intended for the public, allocate sufficient time and resources for translation to ensure that the information will be released in English, French and other languages where applicable.

Community members, other health professionals and agencies outside the network can be informed about network activities through:

- Network member discussions at various meetings and conferences;
- Newsletters, journals, pamphlets and reports;
- Presentations at conferences;
- A network web site;
- Radio, television and newspapers
- MOHLTC regional office staff;
- Involvement of French or French/English media in designated areas.

### **6.2 Building relationships among members**

A commitment to work together on the goal of improving the system of care required by persons with dementia, their families and caregivers needs to be shared by all members. Members need to feel comfortable in raising issues and problem solving in an environment that encourages and values participation from every member.

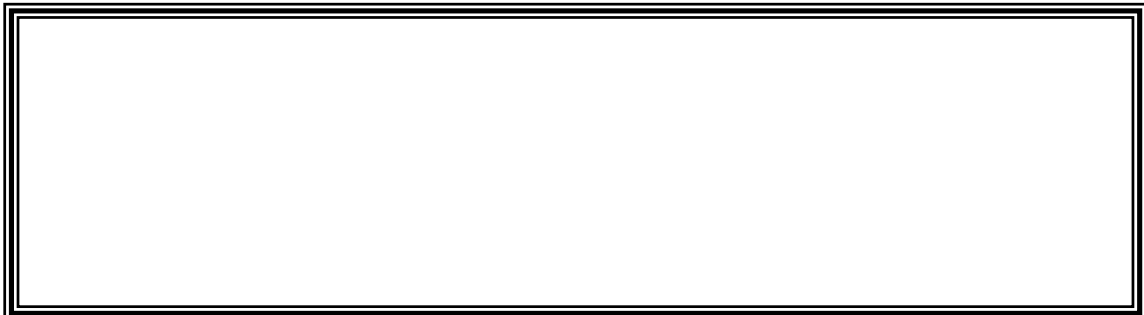
Setting the ground rules early is essential. They should include:

- Respect for all members and the knowledge/experience everyone has to offer;
- Trust and goodwill;
- Non-judgemental;
- Differences and conflict are resolved openly and constructively;
- Openness to change.

### **6.3 Promotion**

Continue to build membership and participation in the network by:

- Influence;
- Persuasion;
- Consensus Building.



## **SECTION 7 – EVALUATION**

### **7.1 Overview of evaluation**

Health networks are inherently complex, therefore it is difficult to measure outcomes and quality. However, it is important to think about evaluation and how it can be used to assess the activities undertaken by a network and for network planning.

In terms of networks, evaluation may be considered in three areas:

- The functioning of the network;
- The evaluation of a particular project being undertaken by the network;  
and
- The impact of the network on the care system.

### **7.2 Evaluating the functioning of the network**

In order to assess how a network functions, the goals and objectives of the network should be clearly defined. Priorities should be identified each year, indicating the specific activities/projects that the network plans to undertake, the specific outcomes that should be achieved, and the time frames for these activities and outcomes. These priorities should be reviewed on an annual basis to assess the progress of the network. Such a review can also assist in planning and priority setting for the following year.

Other activities that can be undertaken to assess how a network is functioning include a regular review of the network's membership and terms of reference. The following can also be used as indicators of a network's functioning:

- Number of meetings held;
- Attendance;
- Products produced, e.g., reports, service agreements;
- Increase/decrease in members;
- Ability to recruit members for committees/work groups;
- Ability to secure resources/supports

### **7.3 Evaluating projects undertaken by the network**

In addition to evaluating the functioning of the network, specific projects that the network undertakes can be evaluated. This process also begins with ensuring that there are clear, measurable goals established for the project. Since some projects have multiple goals, it may be best to determine what goal(s) the network would like to focus on in the evaluation. The next step is to determine how these goals should be assessed. A local university or District Health Council (DHC) may be able to provide some assistance.

## 7.4 Evaluating the impact of the network on the care system

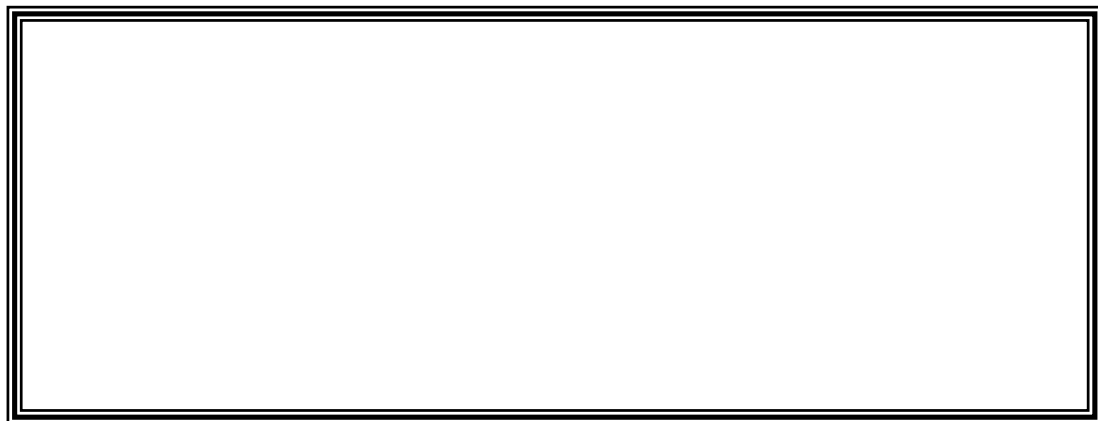
Evaluating the impact that the network has on the care system is a more challenging endeavor. Again, utilizing resources at a local university or DHC is suggested.

Examples of indicators that could be examined include:

- Information sharing
- Access to services
- Managing transitions
- Timeliness
- Quality
- Quality and availability of services in French or other languages, where applicable

When evaluating its impact on the system, the network may want to gather feedback from various perspectives including persons with dementia and their caregivers. This information as well as other evaluation results can then be used to assist network planning and priority setting.

Evaluation takes time, money and expertise. Evaluation goals should be clear and measurable, and evaluation priorities should be determined. It will likely be more worthwhile for a network to take on a smaller evaluation and do it well than to take on a project that may overwhelm the network members in terms of time, resources and energy.



## SECTION 8 – CHALLENGES IN BUILDING CONSENSUS

### 8.1 Settling disagreements among partners

It is helpful to develop a process for resolving conflicts and complaints that cannot be sorted out within the network. Each network will need to determine what arms-length, but supportive organization that can serve as a mediator if needed.

Dementia networks entail a considerable degree of collaboration among organizations and people working together to achieve a common goal. Collaboration often develops in stages through shared communication, cooperation and a shared vision by all members.<sup>21</sup> A written vision and mission statement that has goals clearly defined may assist members in working through challenging issues.

### 8.2 Getting help from other networks

Cultivate contacts in other local dementia networks. Stay in touch with them and contact them to see how they have dealt with similar issues facing your network.

Local dementia networks build on and formalize existing linkages between organizations. They have been attempted in only a few places in Ontario. As a result we need to learn from our own and one another's experiences, using continuous quality improvement processes and a "shared learning" format.

### 8.3 Resolving conflict

*"Everyone wants to participate in decisions that affect them; fewer and fewer people will accept decisions dictated by someone else." (Fisher and Ury, 1981)*

Resolving conflict based on interests rather than positions can help to maintain cordial working relationships.

Positional bargaining can include negotiating from an agency, professional, or ideological perspective. Each side of the issue is argued and a compromise is reached by making concessions. As positions are articulated and 'defended' more attention is paid to stance than to the underlying issues or principles at stake.

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<sup>21</sup> See <http://www.communitycollaboration.net>. For further information, there is considerable literature on building consensus and collaboration.

In contrast, interest based negotiation focuses on the problem and the relationship(s). The conflict generally relates to needs, concerns and fears. By clarifying the perceptions of a situation and determining the needs of the participants, common and compatible outcomes can be found. Resolving the conflict in this way can help to present options, which allow for mutual satisfaction and help to lay the groundwork for future relationships. These relationships will be important to developing an effective network. By participating in the process, individuals will have a stake in the outcome.



## **SECTION 9 – CONCLUSION**

The intent of this Guide is to assist communities in developing or maintaining dementia networks as a way to improve the system of care required by persons with dementia, their families and caregivers. Dementia networks enhance existing relationships/linkages between organizations and provide a means to achieve what autonomous organizations cannot do on their own.

The key steps in dementia network development identified in the Guide include:

### **GETTING STARTED**

- Determine membership**
- Identify key service providers**
- Identify potential leaders**
- Determine your catchment area**
- Consider regional interfaces**

### **INITIAL TASKS**

- Initiate focus groups**
- Engage individuals and organizations across service, education, research, planning and speciality services**
- Complete analysis of community**
- Identify gaps**
- Summarize findings**
- Produce report, distribute and translate, where applicable**
- Set realistic goals for the first year**

### **MAINTAINING THE NETWORK**

- Determine Organizational Structure**
- Clarify Leadership, Function and Responsibility**

### **COMMUNICATION**

- Develop communication mechanism**
- Establish ground rules for network members**
- Establish process to share resources**

### **EVALUATION**

- Determine the goals and objectives**
- Develop the evaluation plan**
- Include feedback from persons with dementia, their families and caregivers.**

## APPENDIX A – RESOURCES

Chronic Care Networks for Alzheimer's Disease, a three-year joint project of the Alzheimer's Association and the National Chronic Care Consortium to design, implement, and evaluate a new model of comprehensive coordinated care for people with Alzheimer's disease and related dementias. Seven community-level partnerships of Alzheimer's Association chapters, comprehensive medical and community-based provider networks address the needs of individuals with various dementias over time and across settings.

April 1999

<http://www.nccconline.org>

John Selstad, Project Co-Director

(612) 814-2643

[jsselstad@nccconline.org](mailto:jsselstad@nccconline.org)

Alzheimer Society of Toronto. A Needs Based Planning Approach Diagram.

Health Networks: Seven Case Studies: A Description and Preliminary Analysis, Ontario Hospital Association, September 1998

<http://www.oha.com>

Pathway to Integration: Identifying Systematic Barriers, Ontario Hospital Association, October 1998

<http://www.oha.com>

Canadian Medical Association Dementia Guidelines, 1999

<http://www.cma.ca/cmaj/vol-160/issue-12/dementia/index.htm>

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<http://www.ofa.gov.on.ca/english/23region/htm#content>

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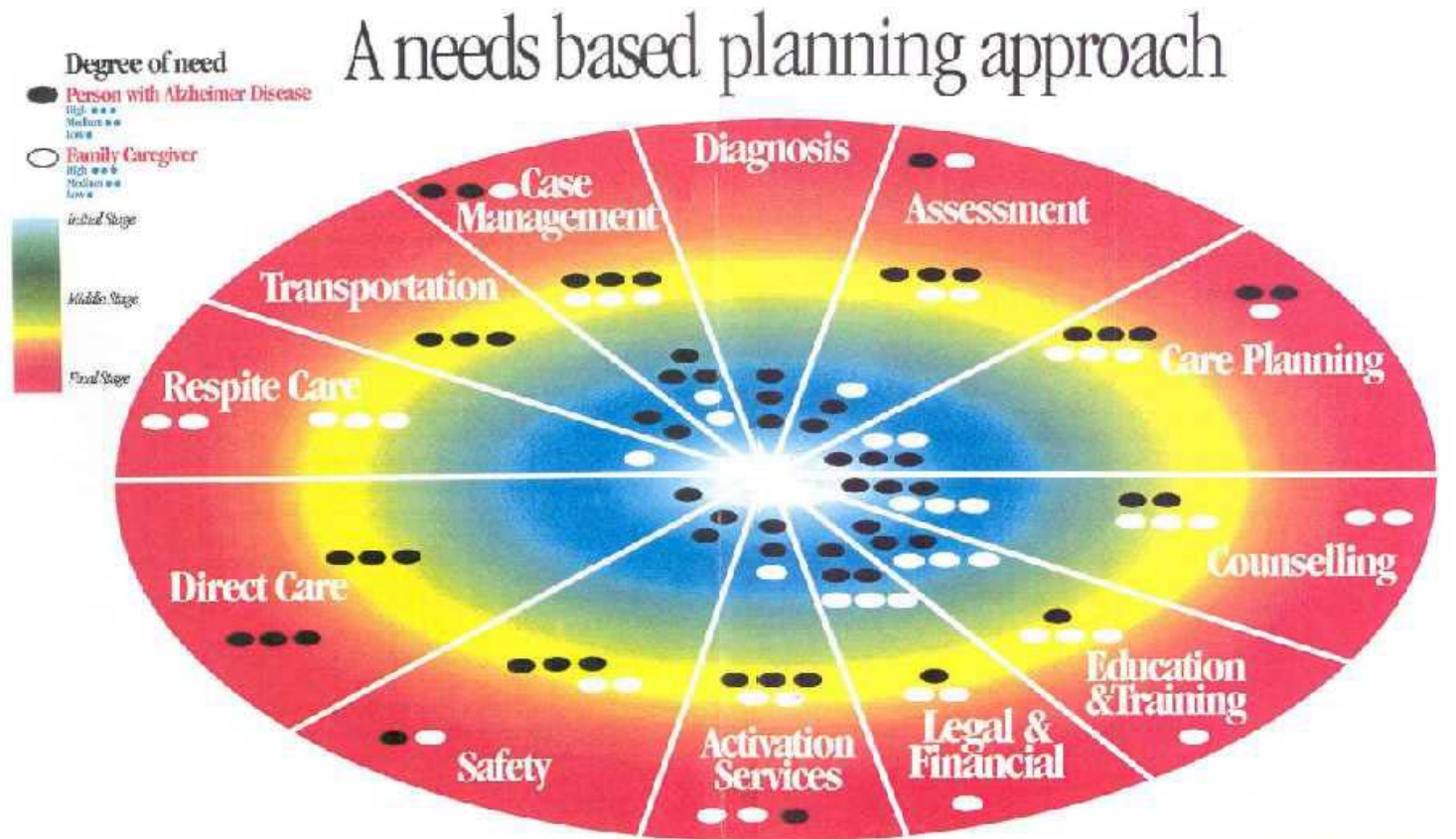
<http://www.gov.on.ca/mczcr/seniors/english/alzheimer-strategy.htm>

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Community Collaboration

<http://www.communitycollaboration.net>

## APPENDIX B – A NEEDS BASED PLANNING APPROACH



Alzheimer Society of Toronto

## APPENDIX C – Ontario Community Geriatric Mental Health Team Exchange 2001

<b>BELLEVILLE</b>	<b>Community Mental Health Program</b> 314 Pinnacle St, 2 <sup>nd</sup> Floor Belleville, Ontario, K8N 3B4  Tel: 613-967-4734	Fax: 613-968-4312
<b>BRANTFORD</b>	<b>Brant County Geriatric Mental Health Outreach Program</b> 97 Mount Pleasant Street Brantford, Ontario, N3T 1T5  Tel: 519-752-9696	Fax: 519-752-8671
<b>BROCKVILLE</b>	<b>Geriatric Psychiatry Community Outreach</b> Brockville Psychiatric Hospital (Division of Royal Ottawa Hospital) PO Box 1050 Brockville, Ontario, K6V 5W7  Tel: 613-498-1493	Fax: 613-498-1495
<b>CAMBRIDGE</b>	<b>Grandside Psychogeriatric Clinic</b> Cambridge Memorial Hospital 700 Coronation Blvd. Cambridge, Ontario, N1R 3G2 Email: <a href="mailto:mentalhealth@cmh.org">mentalhealth@cmh.org</a>  Tel: 519-740-4981	Fax: 519-740-4936
<b>CHATHAM</b>	<b>Community Mental Health Clinic</b> Public General Hospital 106 Emma Street P.O. Box 2030 Chatham, Ontario, N7L 1A8  Tel: 519-351-6144	Fax: 519-351-0450
<b>COLLINGWOOD</b>	<b>Collingwood Community Mental Health Services</b> 459 Hume Street Collingwood, Ontario, L9Y 1W9  Tel: 705-444-6600	Fax: 705-444-5131
<b>CORNWALL</b>	<b>Tri-County Mental Health Services – Psychogeriatric Service</b> 132 Second Street E., Suite 104 Cornwall, Ontario, K6H 1Y4  Tel: 613- 932-9940	Fax : 613- 932-9945

**CORNWALL****Brockville Psychiatric Hospital Division of the Royal Ottawa Health Care Group**

Geropsychiatry Community Outreach Service  
Tri-County Mental Health Services – Psychogeriatric Service  
132 Second Street E., Suite 104  
Cornwall, Ontario, K6H 1Y4

Tel: 613- 932-9940

Fax : 613- 932-9945

**FORT FRANCES****Kenora / Rainy River District Mental Health Services for Older Adults Program**

Canadian Mental Health Association Fort Frances Branch  
Box 446  
612 Portage Avenue  
Fort Frances, Ontario, P9A 3M8

Tel: 807-274-2347

Fax: 807-274-2473

**GUELPH / WELLINGTON & DUFFERIN****Wellington Dufferin Seniors Mental Health**

234 St. Patrick Street East  
Fergus, Ontario, N1M 1M6

Tel: 519-843-6191

Fax: 519-843-7608

**HALDIMAND-NORFOLK****Geriatric Mental Health Program of Haldimand-Norfolk**

26 Main Street N  
P.O. Box 760  
Hagersville, Ontario, N0A 1H0

Tel: 905-768-1101 / Toll Free: 1-877-244-3094 Fax: 905-768-5804

**HAMILTON****Older Adults Program**

St-Joseph's Community and Ambulatory Health Centre  
2757 King Street East  
Hamilton, Ontario, L8G 5E4

Tel: 905-573-4818

Fax: 905-573-4820

**HAMILTON****Psychiatry & Medicine for the Aged in the Community**

Hamilton Health Sciences  
Wilcox Building  
PO Box 2000, 2<sup>nd</sup> Level  
Hamilton, Ontario, L8N 3Z5

Tel: 905-521-7932

Fax: 905-521-7948

**HAWKESBURY****Services de Psychiatrie Gériatrique de Prescott & Russell**

Centre Royal-Comtois  
444 rue McGill, suite 101  
Hawkesbury, Ontario, K6A 1R2

Tel: 613-632-0139

Fax: 613-632-4791

<b>KINGSTON</b>	<p><b>Providence Continuing Care Centre</b>  Mental Health Services  Geriatric Psychiatry Program  752 King Street West  Kingston, Ontario, K7K 1G7</p> <p>Tel: 613-546-1101</p>	<p>Fax: 613-540-6128</p>
<b>LONDON</b>	<p><b>Geriatric Mental Health Program</b>  London Health Sciences Centre  Victoria Campus  375 South Street  London, Ontario, N6A 4G5</p> <p>Tel: 519-667-6693</p>	<p>Fax: 519-667-6707</p>
<b>MILTON (HALTON)</b>	<p><b>Halton Geriatric Mental Health Outreach Program</b>  540 Childs Drive  Milton Ontario L6T 5G1</p> <p>Tel: 905-693-9370</p>	<p>Fax: 905-693-9376</p>
<b>MISSISSAUGA</b>	<p><b>Peel Geriatric Mental Health Services</b>  Trillium Health Centre (Mississauga site)  100 Queensway West  Mississauga, Ontario, L5B 1B8</p> <p>Tel: 905-848-7580 ext 2126</p>	<p>Fax: 905-848-7602</p>
<b>MISSISSAUGA</b>	<p><b>Seniors Mental Health Clinic</b>  Trillium Health Centre (Queensway Site)  4<sup>th</sup> Floor  150 Sherway Drive  Etobicoke, Ontario, M9C 1A5</p> <p>Tel: 416-521-4051</p>	<p>Fax: 416-521-4072</p>
<b>NEWMARKET</b>	<p><b>Southlake Regional Health Centre</b>  Geriatric Mental Health Outreach Program  596 Davis Drive  New Market, Ontario, L3Y 2P9</p> <p>Tel: 905-895-4521</p>	<p>Fax: 905-830-5972</p>
<b>NIAGARA</b>	<p><b>Geriatric Mental Health Outreach Program</b>  301 St. Paul Street, Ste 12  St. Catharines, Ontario, L2R 3M8</p> <p>Tel: 905-704-4068</p>	<p>Fax: 905-704-4072</p>

<b>NORTH BAY</b>	<p><b>Seniors' Mental Health Program – Community Service</b>  200 First Ave W 2<sup>nd</sup> Floor  North Bay, Ontario, P1B 3B9</p> <p>Tel: 705-494-3054 Fax: 705-494-3097</p>
<b>NORTH YORK</b>	<p><b>North York Community Psychogeriatric Service</b>  North York General Hospital  2 Buchan Court  North York, Ontario, M2J 5A3</p> <p>Tel: 416-756-6050 Fax: 416-756-3144</p>
<b>OTTAWA</b>	<p><b>Psychogeriatric Community Services of Ottawa</b>  75 Bruyère Street, Room 106Y  Ottawa, Ontario, K1N 5C8</p> <p>Tel: 613-562-9777 Fax: 613-562-0259</p>
<b>OTTAWA</b>	<p><b>Geriatric Psychiatry Outreach Service</b>  Geriatric Psychiatry Program  Royal Ottawa Hospital  1145 Carling Ave  Ottawa, Ontario, K1Z 7K4</p> <p>Tel: 613-722-6521 ext 6927 Fax: 613-798-2999</p>
<b>PEMBROKE</b>	<p><b>Renfrew County Geriatric Mental Health Outreach Team</b>  Marianhill Inc  600 Cecelia Street  Pembroke, Ontario, K8A 7Z3</p> <p>Tel: 613-735-6868 Fax: 613-732-3934</p>
<b>PENETANGUISHENE</b>	<p><b>Geriatric Services Program - Outreach Services</b>  c/o Mental Health Centre  500 Church St  Penetanguishene, Ontario, L9M 1G3</p> <p>Tel: 705-549-3181 ext 2644 (Toll free: 1-877-341-4729) Fax: 705-549-0266</p>
<b>PETERBOROUGH</b>	<p><b>Psychiatric Assessment Services for the Elderly (PASE)</b>  Peterborough Regional Health Centre  1 Hospital Drive  Peterborough, Ontario, K9J 7C6</p> <p>Tel: 705-876-5076 Fax: 705-876-5160</p>

<b>PICTON</b>	<p><b>Community Mental Health Program</b>  43 Main St, Box 1346  Picton, Ontario, K0K 2T2  Email: <a href="mailto:cmhppicton@bel.auracom.com">cmhppicton@bel.auracom.com</a></p> <p>Tel: 6123-476-2990</p> <p style="text-align: right;">Fax: 613-476-6403</p>
<b>RICHMOND HILL</b>	<p><b>Psychogeriatric Clinic, Mental Health Program</b>  York Central Hospital  10 Trench Street  Richmond Hill, Ontario, L4C 4Z3</p> <p>Tel: 905-883-2592</p> <p style="text-align: right;">Fax: 905-883-2292</p>
<b>SARNIA</b>	<p><b>Lampton Psychogeriatric Consultation Service</b>  c/o Sarnia General Hospital  220 N Mitton Street  Sarnia, Ontario, N7T 6H6</p> <p>Tel: 519-464-4533</p> <p style="text-align: right;">Fax: 519-464-4516</p>
<b>SAULT STE. MARIE</b>	<p><b>Seniors Mental Health Services</b>  390 Bay Street, 4<sup>th</sup> Floor  Sault Ste. Marie, Ontario, P6A 1X2</p> <p>Tel: 705-759-9396</p> <p style="text-align: right;">Fax: 705-759-3235</p>
<b>SMITHS FALLS</b>	<p><b>Lanark County Mental Health</b>  Seniors Resource Team  Geriatric Psychiatry Outreach Program  88 Cornelia St, West, Unit 2A  Smiths Falls, Ontario, K7A 5K9</p> <p>Tel: 613-283-2170</p> <p style="text-align: right;">Fax: 613-283-9018</p>
<b>STRATFORD</b>	<p><b>Seniors Mental Health Program</b>  Special Services Building  90 John Street South  Stratford, Ontario, N5A 2Y8</p> <p>Tel: 519-272-8210 ext 2205</p> <p style="text-align: right;">Fax: 519-272-8226</p>
<b>SUDBURY</b>	<p><b>Sudbury Regional Hospital</b>  Psychogeriatric Outreach Program  584 Clinton Ave  Sudbury, Ontario, P3E 2T2</p> <p>Tel: 705-671-3186</p> <p style="text-align: right;">Fax: 705-671-4041</p>



<b>THUNDER BAY</b>	<p><b>Community Outreach Team (Older Adult Mental Health)</b> St. Joseph's Heritage 63 Carrie Street Thunder Bay, Ontario, P7A 4J2</p> <p>Tel: 807-768-4448</p>	<p>Fax: 807-768-4452</p>
<b>THUNDER BAY</b>	<p><b>Psychogeriatric Community Assessment Program</b> Lakehead Psychiatric Hospital 580 N. Algoma Street, PO Box 2930 Thunder Bay, Ontario, P7B 5G4</p> <p>Tel: 807-343-4368</p>	<p>Fax: 807-343-4387</p>
<b>TORONTO</b>	<p><b>Geriatric Psychiatry Community Service Baycrest Hospital</b> 3560 Bathurst Street Toronto, Ontario, M6A 2E1</p> <p>Tel: 416-785-2500 ext 2730</p>	<p>Fax: 416-785-2492</p>
<b>TORONTO</b>	<p><b>COTA's Psychogeriatric Team</b> 700 Lawrence Avenue West, suite 362 Toronto, Ontario, M6A 3B4</p> <p>Tel: 416-785-9230</p>	<p>Fax: 416-785-9358</p>
<b>TORONTO</b>	<p><b>P.A.C.E. Central</b> Centre for Addiction &amp; Mental Health 1001 Queen Street West Toronto, Ontario, M6J 1H4</p> <p>Tel: 416-583-4326</p>	<p>Fax: 416-326-1478</p>
<b>TORONTO</b>	<p><b>P.A.C.E. East</b> Centre for Addiction &amp; Mental Health Queen St. Site 393 King Street East Toronto, Ontario, M5A 1L3</p> <p>Tel: 416-535-8501 ext.7650</p>	<p>Fax: 416-865-0540</p>
<b>TORONTO</b>	<p><b>P.A.C.E. West</b> Centre for Addiction &amp; Mental Health Queen St. Site 1001 King Street West Toronto, Ontario, M6J 1H4</p> <p>Tel: 416-535-8501 ext.2692</p>	<p>Fax: 416-583-1307</p>

<b>TORONTO</b>	<p><b>Saint Elizabeth Health Care</b>          Psychogeriatric Team          Toronto Service Delivery Centre          2 Lansing Square, Suite 600          Toronto, Ontario, M2J 4P8</p> <p>Tel: 416-498-7936</p>	<p>Fax: 416-498-7936</p>
<b>TORONTO</b>	<p><b>Community Psychiatric Services for the Elderly (CPSE)</b>  <b>Sunnybrook and Women's College Health Sciences Centre</b>          Room F307,          2075 Bayview Avenue          Toronto, Ontario, M4N 3M5</p> <p>Tel: 416-480-4663</p>	<p>Fax: 416-480-5889</p>
<b>TORONTO</b>	<p><b>Seniors Health Services</b>  <b>West Park Healthcare Centre</b>          82 Buttonwood Avenue          Toronto, Ontario, M6M 2J5</p> <p>Tel: 416-243-3732</p>	<p>Fax: 416-243-3735</p>
<b>WATERLOO</b>	<p><b>Waterloo Region Community Geriatric Services</b>          99 Regina Street S., Box 1612          Waterloo, Ontario          N2J 4G6</p> <p>Tel: 519 883 - 5500 Ext. 5067</p>	<p>Fax: 519-883 - 5555</p>
<b>WHITBY</b>	<p><b>Seniors Mental Health Program</b>          Whitby Mental Health Centre          700 Gordon Street, Box 613          Whitby, Ontario, L1N 5S9</p> <p>Tel: 905-668-5881 ext 6298</p>	<p>Fax: 905-430-4032</p>
<b>WINDSOR</b>	<p><b>The Mental Health Program for Older Adults (jointly sponsored)</b>          Canadian Mental Health Association          1400 Windsor Ave.          Windsor, Ontario, N8X 3L9</p> <p>Tel: 519-255-7440</p>	<p>Fax: 519-255-7817</p>
<b>WINDSOR</b>	<p><b>The Mental Health Program for Older Adults (jointly sponsored)</b>          Windsor Regional Hospital          1453 Prince Rd.          Windsor, Ontario, N9C 3Z4</p> <p>Tel: 519-257-5105</p>	<p>Fax: 519-257-5188</p>

## Regional Geriatric Programs

**Hamilton** Specialized Health Care for the Elderly Regional Program  
Henderson Hospital  
711 Concession Street  
Hamilton, ON L8V 1C3  
Tel: 905-574-6244  
Fax: 905-575-5121

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**Kingston** Southeastern Ontario Regional Geriatric Program  
Providence Continuing Care Centre  
St. Mary's of the Lake Hospital  
340 Union Street, P. O. Box 3600  
Kingston, ON K7L 5A2  
Tel: 613-548-7222  
Fax: 613-544-4017

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**London** Southwestern Ontario Regional Geriatric Program  
801 Commissioners Road, East  
London, ON N6C 5J1  
Tel: 519-685-4069  
Fax: 519-685-4068

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**Ottawa** Ottawa-Carlton Regional Geriatric Assessment Program  
Ottawa Hospital, Civic Campus  
1053 Carling Avenue, 1<sup>st</sup> Floor  
Ottawa, ON K1Y 4E9  
Tel: 613-761-4568  
Fax: 613-761-5334

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**Toronto** Metropolitan Toronto Regional Geriatric Program  
Sunnybrook & Women's College Health Sciences Centre  
2075 Bayview Avenue  
Toronto, ON M4N 3M5  
Tel: 416-480-6802  
Fax: 416-480-6068

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## Alzheimer Society of Ontario Offices

#202 - 1200 Bay Street  
Toronto, Ontario  
M5R 2A5  
Phone: 416-967-5900  
Fax: 416-967-3826  
E-mail: [alzheimeront@sympatico.ca](mailto:alzheimeront@sympatico.ca)

### Alzheimer Society of Belleville-Hastings

470 Dundas Street  
Belleville, ON K8N 1G1  
Telephone: (613) 962-0892  
Fax: (613) 962-1225  
E-Mail: [alzheimer.society.belleville-hastings@sympatico.ca](mailto:alzheimer.society.belleville-hastings@sympatico.ca)

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### Alzheimer Society of Brant

101 Brant Avenue  
Brantford, ON N3T 3H4  
Telephone: (519) 759-7692  
Fax: (519) 759-8353  
E-Mail: [alzbrant@bfree.on.ca](mailto:alzbrant@bfree.on.ca)

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### Alzheimer Society of Cambridge

614 Coronation Blvd., Ste. 103  
Cambridge, ON N1R 3E8  
Telephone: (519) 622-6066  
Fax: (519) 622-4454  
E-Mail: [alzcam@golden.net](mailto:alzcam@golden.net)

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### Alzheimer Society of Chatham-Kent

36 Memory Lane  
Chatham, ON N7L 5M8  
Telephone: (519) 352-1043  
Fax: (519) 352-3680  
E-Mail: [alzeime@MNSI.com](mailto:alzeime@MNSI.com)

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### Alzheimer Society of Cornwall & District

P.O. Box 1852  
Cornwall, ON K6H 6N6  
Telephone: (613) 932-4914  
Fax: (613) 932-6154  
E-Mail: [alzheimer@on.aibn.com](mailto:alzheimer@on.aibn.com)  
Courier address:  
55 Water St. W., Ste. 220  
Cornwall, ON K6J 1A1

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**Alzheimer Society of Dufferin County**

32 First St., Lower Level  
Orangeville, ON L9W 2E1  
Telephone: (519) 941-1221  
Fax: (519) 941-1730  
E-Mail: [alzdufferincounty@on.aibn.com](mailto:alzdufferincounty@on.aibn.com)

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**Alzheimer Society of Durham Region**

419 King St.W., Ste. 205  
Oshawa, ON L1J 2K5  
Telephone: (905) 576-2567  
1-888-301-1106  
Fax: (905) 576-2033  
E-Mail: [alzheimerdurham@oix.com](mailto:alzheimerdurham@oix.com)

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**Alzheimer Society of Elgin-St. Thomas**

98 Centre Street  
St. Thomas, ON N5R 2Z7  
Telephone: (519) 633-4396  
1-888-565-1111  
Fax: (519) 633-7028  
E-Mail: [remember@execulink.com](mailto:remember@execulink.com)

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**Alzheimer Society of Greater Simcoe Country**

P.O. Box 1414  
Barrie, ON L4M 5R4  
Telephone: (705) 722-1066  
Fax: (705) 722-9392  
E-Mail: [alzgsc@csolve.net](mailto:alzgsc@csolve.net)  
Courier address:  
12 Fairview Rd., Ste. 103  
Barrie, ON L4N 4P3

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**Alzheimer Society of Grey-Bruce**

769 Second Ave. E.  
Owen Sound, ON N4K 2G9  
Telephone: (519) 376-7230  
Fax: (519) 376-2428  
E-Mail: [alzheimer@bmts.com](mailto:alzheimer@bmts.com)

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**Alzheimer Society of Guelph-Wellington**

111 Macdonell St.  
Guelph, ON N1H 2Z7  
Telephone: (519) 836-7672  
Fax: (519) 836-1041  
E-Mail: [office@alzheimer.guelph.org](mailto:office@alzheimer.guelph.org)

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**Alzheimer Society of Haldimand-Norfolk**

365 West St., PO Box 391  
Simcoe, ON N3Y 4L2  
Telephone: (519) 428-7771  
Fax: (519) 428-2968  
E-Mail: [alzhn@kwic.com](mailto:alzhn@kwic.com)

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**Alzheimer Society for Halton-Wentworth**

1685 Main St.W., Ste. 206  
Hamilton, ON L8S 1G5  
Telephone: (905) 529-7030  
Fax: (905) 529-3787  
E-Mail: [alzhhw@interlynx.net](mailto:alzhhw@interlynx.net)

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**Alzheimer Society of Huron County**

P.O. Box 639,  
Clinton, ON NOM ILO  
Telephone: (519) 482-1482  
Fax: (519) 482-8692  
E-Mail: [alzhuiron@scsinternet.com](mailto:alzhuiron@scsinternet.com)  
Courier address:  
317 Huron Street, (off Highway 8)  
Clinton, ON NOM ILO

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**Alzheimer Society of Kenora & District**

Box 837  
Kenora, ON P9N 4B5  
Telephone: (807) 468-1516  
Fax: (807) 468-1516  
E-Mail: [alzheimers@kenora.com](mailto:alzheimers@kenora.com)  
Courier address:  
Old St. Joe's Hospital  
1st Floor, Ocean Ave.  
Kenora, ON P9N 3W7

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**Alzheimer Society of Kingston**

100 Stuart Street  
Kingston, ON K7L 2V6  
Telephone: (613) 544-3078  
Fax: (613) 544-6320  
E-Mail: [alzking@kos.net](mailto:alzking@kos.net)

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**Alzheimer Society of Kitchener-Waterloo**

151 Frederick, Ste. 501  
Kitchener, ON N2H 2M2  
Telephone: (519) 742-1422  
Fax: (519) 742-1862  
E-Mail: [alzkw@nonline.net](mailto:alzkw@nonline.net)

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**Alzheimer Society of Lanark County**

33 Drummond St W.  
Perth, ON K7H 2K1  
Telephone: (613) 264-0307  
Fax: (613) 264-8430  
E-Mail: [alz@superaje.com](mailto:alz@superaje.com)

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**Alzheimer Society of Leeds-Grenville**

P.O. Box 1836  
Brockville, ON K6V 6K9  
Telephone: (613) 345-7392  
Fax: (613) 345-3186  
Courier address:  
Alzheimer Society of Leeds-Grenville  
42 George Street  
Brockville, K6V 3V5

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**Alzheimer Society of London and Middlesex**

555 Southdale Rd. E., Ste. 100  
London, ON N6E 1A2  
Telephone: (519) 680-2404  
Fax: (519) 680-2864  
E-Mail: [alzheimer.info@cims.net](mailto:alzheimer.info@cims.net)

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**Alzheimer Society of Muskoka**

98 Pine Street  
Bracebridge, ON P1L 1N5  
Telephone: (705) 645-5621  
Fax: (705) 645-4397  
E-Mail: [alzmusk@muskoka.com](mailto:alzmusk@muskoka.com)

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**Alzheimer Society of Niagara Region**

203 Ontario St.  
St. Catharines, ON L2R 5L2  
Telephone: (905) 687-3914  
Fax: (905) 687-9952  
E-Mail: [asnr@jaw.on.ca](mailto:asnr@jaw.on.ca)

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**Alzheimer Society of North Bay & District**

269 Main St. W., Ste. 204  
North Bay, ON P1B 2T8  
Telephone: (705) 495-4342  
Fax: (705) 495-0329  
E-Mail: [asnb@volnetmmp.net](mailto:asnb@volnetmmp.net)

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**Alzheimer Society of North East Simcoe County**

P.O. Box 486  
Orillia, ON L3V 6K2  
Telephone: (705) 329-0909  
Fax: (705) 329-2378  
E-Mail: [info@alzheimerorillia.com](mailto:info@alzheimerorillia.com)  
Courier address:  
12 Grace Ave.  
Orillia, ON L3V 2K2

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**Alzheimer Society of Ottawa-Carleton**

1750 Russell Rd.  
Ottawa, ON K1G 5Z6  
Telephone: (613) 523-4004  
Fax: (613) 523-8522  
E-Mail: [asoc@cyberus.ca](mailto:asoc@cyberus.ca)

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**Alzheimer Society of Oxford**

575 Peel St.  
Woodstock, ON N4S 1K6  
Telephone: (519) 421-2466  
Fax: (519) 421-3098  
E-Mail: [info@alzheimer.oxford.on.ca](mailto:info@alzheimer.oxford.on.ca)

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**Alzheimer Society of Peel**

60 Briarwood Ave.  
Mississauga, ON L5G 3N6  
Telephone: (905) 278-3667  
Fax: (905) 278-3964  
E-Mail: [alzheimersocietypeel@home.com](mailto:alzheimersocietypeel@home.com)

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**Alzheimer Society of Perth County**

311 Church St.  
Stratford, ON N5A 2R9  
Telephone: (519) 271-1910  
Fax: (519) 271-1231  
E-Mail: [alzperth@cyg.net](mailto:alzperth@cyg.net)

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**Alzheimer Society of Peterborough**

P.O. Box 1701  
Peterborough, ON K9J 7S4  
Telephone: (705) 748-5131  
Fax: (705) 748-6174  
E-Mail: [aspaptbo@sympatico.ca](mailto:aspaptbo@sympatico.ca)  
Courier address:  
183 Simcoe St.  
Peterborough, ON K9H 2H6

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**Alzheimer Society of Prince Edward County**

P.O. Box 980  
Picton, ON K0K 2T0  
Telephone: (613) 476-2085  
Fax: (613) 476-1537  
E-Mail: [aspec@mail.reach.net](mailto:aspec@mail.reach.net)  
Courier address:  
90 King St.  
Picton, ON K0K 2T0

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**Alzheimer Society of Sarnia-Lambton**

110 Water St.  
Sarnia, ON N7T 5T3  
Telephone: (519) 332-4444  
Fax: 519) 332-6673  
E-Mail: [alzheimerebtech.net](mailto:alzheimerebtech.net)

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**Alzheimer Society of Sault Ste. Marie & Algoma District**

633 Albert St. E.  
Sault Ste. Marie, ON P6A 2K5  
Telephone: (705) 942-2195  
Fax: 705) 256-6777  
E-Mail: [alzssm@volnetmmp.net](mailto:alzssm@volnetmmp.net)

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**Alzheimer Society of Sudbury-Manitoulin**

970 Notre Dame Ave.  
Sudbury, ON P3A 2T4  
Telephone: (705) 560-0603  
Fax: (705) 560-6938  
E-Mail: [alzhsud@isys.ca](mailto:alzhsud@isys.ca)

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**Alzheimer Society of Thunder Bay**

180 Park Ave., Ste. 310  
Thunder Bay, ON P7B 6J4  
Telephone: (807) 345-9556  
Fax: (807) 345-1518  
E-Mail: [alzheimertb@norlink.net](mailto:alzheimertb@norlink.net)

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**Alzheimer Society of Timmins-Porcupine District**

690 River Park Rd., Unit 206  
Timmins, ON P4P 1B4  
Telephone: (705) 268-4554  
Fax: (705) 360-4492

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**Alzheimer Society of Toronto**

2323 Yonge St., Ste. 500  
Toronto, ON M4P 2C9  
Telephone: (416) 322-6560  
Fax: (416) 322-6656  
E-Mail: [write@asmt.org](mailto:write@asmt.org)

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**Alzheimer Society of Victoria County**

P.O. Box 730  
Lindsay, ON K9V 4W9  
Telephone: (705) 878-0126  
Fax: (705) 878-0127  
E-Mail: [alzvic@on.aibn.com](mailto:alzvic@on.aibn.com)  
Courier address:  
55 St. Mary St. W., Ste. 201  
Gate Way Plaza  
Lindsay, ON K9V 5Z6

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**Alzheimer Society of Windsor-Essex County**

242 Lauzon Road  
Windsor, ON N8S 3L6  
Telephone: (519) 974-2220  
Fax: (519) 974-9727  
E-Mail: [alzwind@wincom.net](mailto:alzwind@wincom.net)

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**Alzheimer Society of York Region**

800 Davis Drive, Unit 6  
Newmarket, ON L3Y 2R5  
Telephone: (905) 895-1337  
Fax: (905) 895-1736  
E-Mail: [daycn@idirect.com](mailto:daycn@idirect.com)

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## Community Care Access Centres

### **Access Centre For Hastings and Prince Edward Counties**

Bayview Mall  
470 Dundas Street East  
Belleville, Ontario  
K8N 1G1  
Tel : (613) 966-3530  
Fax: (613) 966-0996

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### **Access Centre For Community Care in Lanark, Leeds and Grenville**

52 Abbott Street North, Unit 1  
Smith Falls, Ontario  
K7A 1W3  
Tel : (613) 283-8012 or 1-800-267-6041  
Fax: (613) 283-0308

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### **Algoma Community Care Access Centre**

(Services available in French)  
390 Bay Street, 2nd Floor  
Sault Ste. Marie, Ontario  
P6A 1X2  
Tel : (705) 949-1650  
Fax: (705) 949-1663

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### **Brant Community Care Access Centre**

274 Colborne Street  
Brantford, Ontario  
N3T 2H5  
Tel : (519) 759-7752  
Fax: (519) 759-7130

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### **Chatham/Kent Community Care Access Centre**

(Services available in French)  
750 Richmond Street, Box 306  
Chatham, Ontario  
N7M 5K4  
Tel : (519) 436-2222  
Fax: (519) 351-5842

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### **Cochrane District Community Care Access Centre**

(Services available in French)  
60 Wilson Avenue, 3rd Floor  
Timmins, Ontario  
P4N 2S7  
Tel : (705) 267-7766 or 1-888-668-2222  
Fax: (705) 267-7795

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**Community Care Access Centre of The District of Thunder Bay**

(Services available in French)  
1159 Alloy Drive, Suite 200  
Thunder Bay, Ontario  
P7B 6M8  
Tel : (807) 345-7339 or 1-800-626-5406  
Fax: (807) 345-8868  
Web: [www.ccac-tb.on.ca](http://www.ccac-tb.on.ca)

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**Community Care Access Centre for Eastern Counties**

(Services available in French)  
709 Cotton Mill Street  
Cornwall, Ontario  
K6H 7K7  
Tel : (613) 936-1171 or 1-800-267-0852  
Fax: (613) 936-0644

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**Community Care Access Centre of Halton**

440 Elizabeth Street, 4th Floor  
Burlington, Ontario  
L7R 2M1  
Tel : (905) 639-5228 or 1-800-810-0000 (905 and 519 areas)  
Fax: (905) 639-5320  
Web : [www.ccac-halton.on.ca](http://www.ccac-halton.on.ca)

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**Community Care Access Centre For Huron**

c/o Health and Library Complex  
P.O.Box 459, 163 Princess Street East  
Clinton, Ontario  
N0M 1L0  
Tel : (519) 482-3411 or 1-800-267-0535 (519 area only)  
Fax: (519) 482-1485

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**Community Care Access Centre for Kenora and Rainy River Districts**

(Services available in French)  
21 Wolsley Street  
Kenora, Ontario  
P9N 3W7  
Tel : (807) 310-4636 or 1-877-661-6621 (outside 807 area)  
Fax: (807) 468-1437  
Web : [communitycare.on.ca](http://communitycare.on.ca)

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**Community Care Access Centre of London & Middlesex**

(Services available in French)

356 Oxford Street West

London, Ontario

N6A 5L7

Tel : (519) 473-2222 or leave Voice Mail at (519) 641-1113

Fax: (519) 472-4045

Web : [www.ccaclm.on.ca](http://www.ccaclm.on.ca)

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**Community Care Access Centre Niagara**

(Mail only) P.O. Box 215, St. Catharines, Ontario, L2R 6S4, Canada

(Location) (RR4) 509 Glendale Avenue, Niagara-o/t-Lake, Ontario, L0S 1J0, Canada

Tel : (905) 684-9441

Fax: (905) 684-8463

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**Community Care Access Centre Oxford**

1147 Dundas Street

Woodstock, Ontario

N4S 8W3

Tel : (519) 539-1284

Fax: (519) 539-0065

Web : [www.ocl.net/projects/community\\_care](http://www.ocl.net/projects/community_care)

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**Community Care Access Centre of Peel**

(Services available in French)

199 County Court Boulevard

Brampton, Ontario

L6W 4P3

Tel : (905) 796-0040 or 1-888-733-1177

Fax: (905) 796-5620

Web : [www.ccacpeel.org](http://www.ccacpeel.org)

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**Community Care Access Centre Timiskaming**

(Services available in French)

P.O. Box 520, 111 Burnside Drive

Kirkland Lake, Ontario

P2N 3J5

Tel : (705) 567-2222

Fax: (705) 567-9407

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**Community Care Access Centre of Waterloo Region**

99 Regina Street South, 4th Floor

Box 1612

Waterloo, Ontario

N2J 4G6

Tel : (519) 883-5500

Fax: (519) 883-5555

Web : [www.ccacwat.on.ca](http://www.ccacwat.on.ca)

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**Community Care Access Centre of Wellington - Dufferin**

450 Speedvale Avenue West, Suite 201

Guelph, Ontario

N1H 7G7

Tel : (519) 823-2550

Fax: (519) 823-8682

Web : [www.ccacwd.org](http://www.ccacwd.org)

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**Community Care Access Centre Windsor/Essex**

(Services available in French)

339 Crawford Avenue, 5th Floor

Windsor, Ontario

N9A 5C6

Tel : (519) 258-8211

Fax: (519) 258-6288 - Intake)

Fax: (519) 258-2004 - Admin.)

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**Community Care Access Centre of York Region**

1100 Gorham Street, Unit 1

Newmarket, Ontario

L3Y 7V1

Tel : (905) 895-1240 or (416) 221-3212 or

Toll: 1-888-470-CCAC (2222) (for 905, 416, 705, 519 areas only)

Fax: (905) 853-6297

Web : [www.ccacyorkregion.on.ca](http://www.ccacyorkregion.on.ca)

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**Durham Access to Care**

Whitby Corporate Centre

209 Dundas St. E, 5th Floor

Whitby, Ontario

L1N 7H8

Tel : (905) 430-3308 or 1-800-263-3877

Fax: (905) 430-3297

Web : [www.datc.org](http://www.datc.org)

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**East York Access Centre For Community Services**

(Services available in French)

1 Leaside Park Drive

Toronto (East York), Ontario

M4H 1R1

Tel : (416) 423-3559

Fax: (416) 423-9800

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**Etobicoke Community Care Access Centre**

(Services available in French)  
401 The West Mall, Suite 101  
Toronto (Etobicoke), Ontario  
M9C 5J5  
Tel : (416) 626-2222  
Fax: (416) 626-9683  
Web : [www.etobicokeccac.com](http://www.etobicokeccac.com)

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**Elgin Community Care Access Centre**

294 Talbot Street  
St. Thomas, Ontario  
N5P 4E3  
Tel: (519) 631-9907  
Fax: (519) 631-2236

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**Grey/Bruce Community Care Access Centre**

255 - 18th Street West  
Owen Sound, Ontario  
N4K 6Y1  
Canada  
Tel : (519) 371-2112 or 1-888-371-2112  
Fax: (519) 371-5612 or 1-800-825-7126  
Web : [www.g-bccac.org](http://www.g-bccac.org)

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**Haldimand-Norfolk Community Care Access Centre**

76 Victoria Street  
Simcoe, Ontario  
N3Y 1L5  
Tel : (519) 426-7400  
Fax: (519) 426-4384  
Web : [www.hnccac.on.ca](http://www.hnccac.on.ca)

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**Haliburton, Northumberland & Victoria LTC Access Centre**

108 Angeline Street South  
Lindsay, Ontario  
K9V 3L5  
Tel : (705) 324-9165  
Fax: (705) 324-0884  
Web : [www.hnvaccesscentre.on.ca](http://www.hnvaccesscentre.on.ca)

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**Hamilton/Wentworth Community Care Access Centre**

(Services available in French)  
310 Limeridge Road West  
Hamilton, Ontario  
L9C 2V2  
Tel : (905) 523-8600  
Fax: (905) 528-1883  
Web : [www.hwccac.on.ca](http://www.hwccac.on.ca)

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**Kingston, Frontenac, Lennox & Addington Community Care Access Centre**

471 Counter Street, Suite 101

Kingston, Ontario

K7M 8S8

Tel : (613) 544-7090

Fax: (613) 544-1494

Web : [www.kfla-cc.org](http://www.kfla-cc.org)

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**Manitoulin - Sudbury Community Care Access Centre**

(Services available in French)

1760 Regent Street

Sudbury, Ontario

P3E 3Z8

Tel : (705) 522-3460 or 1-800-461-2919

Fax: (705) 522-3855

Web : [library.utoronto.ca/www/aging/onpea\\_projects/msccac.html](http://library.utoronto.ca/www/aging/onpea_projects/msccac.html)

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**Muskoka East Parry Sound Community Care Access Centre**

(A Division of Algonquin Health Services)

354 Muskoka Road No.3 North

Huntsville, Ontario

P1H 1H7

Tel : (705) 789-6451

Fax: (705) 789-1982

Web : [www.algonquinhs.on.ca](http://www.algonquinhs.on.ca)

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**Near North Community Care Access Centre (Nipissing)**

(Services available in French)

101 McIntyre Street West, 3rd Floor

North Bay, Ontario

P1B 2Y5

Tel : (705) 476-2222 or 1-888-533-2222 (705 area only)

Fax: (705) 474-0080

Web : [www.library.utoronto.ca/www/aging/onpea\\_projects/nbccac.html](http://www.library.utoronto.ca/www/aging/onpea_projects/nbccac.html)

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**North York Community Care Access Centre**

(Services available in French)

45 Sheppard Avenue East, Suite 700

Toronto (Willowdale), Ontario

M2N 5W9

Tel : (416) 222-2241

Fax: (416) 229-6809

Web : [www.nyccac.on.ca](http://www.nyccac.on.ca)

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**Ottawa-Carleton Community Care Access Centre**

(Services available in French)  
1223 Michael Street North, Suite 410  
Gloucester, Ontario  
K1J 7T2  
Tel : (613) 745-5525  
Fax: (613) 745-6984

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**Perth County Community Care Access Centre**

65 Lorne Avenue East  
Stratford, Ontario  
N5A 6S4  
Tel : (519) 273-2222  
Fax: (519) 273-2139

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**Peterborough Community Care Access Centre**

700 Clonsilla Avenue, Suite 202  
Peterborough, Ontario  
K9J 5Y3  
Tel : (705) 743-2212 or 1-888-235-7222  
Fax: (705) 743-9559  
Web : [www.accesscentre.on.ca](http://www.accesscentre.on.ca)

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**Renfrew County Community Care Access Centre**

7 International Drive, Suite B  
Pembroke, Ontario  
K8A 6W5  
Canada  
Tel : (613) 732-7007 or 1-888-421-2222  
Fax: (613) 732-3522  
Web : [www.ccacrenfrew.org](http://www.ccacrenfrew.org)

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**Sarnia Lambton Community Care Access Centre**

1433 London Road  
Sarnia, Ontario  
N7T 7H9  
Tel : (519) 542-4444 or 1-800-265-1445  
Fax: (519) 542-3116  
Web : [www.s-lccac.on.ca](http://www.s-lccac.on.ca)

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**Scarborough Community Care Access Centre**

1940 Eglinton Avenue East, 3rd Floor  
Toronto (Scarborough), Ontario  
M1L 4R1  
Tel : (416) 750-2444 (main)  
Fax: (416) 750-8234  
Web : [www.scarbcccac.org](http://www.scarbcccac.org)

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**Simcoe County Community Care Access Centre**

(Services available in French)  
15 Sperling Drive, Suite 100  
Barrie, Ontario  
L4M 6K9  
Tel : (705) 721-7444 or 1-888-721-2222  
Fax: (705) 722-5237  
Web : [www.ccacsc.on.ca](http://www.ccacsc.on.ca)

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**Toronto Community Care Access Centre**

(Services available in French)  
250 Dundas Street West, Ground Floor, Unit 5  
Toronto, Ontario  
M5T 2Z5  
Tel : (416) 506-9888  
Fax: (416) 506-0374

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**West Parry Sound Health Centre CCAC**

10 James Street  
Parry Sound, Ontario  
P2A 1T3  
Tel : (705) 746-4540  
Fax: (705) 746-7364

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**York Community Care Access Centre (Former City of York)**

(Services available in French)  
1400 Castlefield Avenue  
Toronto, Ontario  
M6B 4C4  
Tel : (416) 780-1919  
Fax: (416) 780-1749

## APPENDIX D – Dementia Networks Work Group Membership

**Ken Le Clair, M.D. (Chair)**

Clinical Director  
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Providence Continuing Care Centre  
Mental Health Services  
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[leclairk@pccc.kari.net](mailto:leclairk@pccc.kari.net)

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Director, Program Development and  
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St. Joseph and University Hospital of  
Western Ontario  
London  
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Community Care Access Centre for Huron  
Huron Geriatric Assessment Team  
Clinton  
[pgordon@ccac-huron.org](mailto:pgordon@ccac-huron.org)

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Department of Health Policy, Management  
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Toronto  
[l.lemieux.charles@utoronto.ca](mailto:l.lemieux.charles@utoronto.ca)

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Long-Term Care Policy Consultant &  
Faculty Member, University of Toronto,  
Faculty of Social Work and Faculty of  
Medicine  
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**Joe McReynolds**

Executive Director  
Ontario Community Support Association  
Toronto  
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Services  
City of Greater Sudbury  
Sudbury  
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Relations  
Alzheimer Society of Ontario  
Toronto  
[lmoore@alzheimeront.org](mailto:lmoore@alzheimeront.org)

**Carla Pepler**

Resident Care Program Design Consultant  
Nurse Practitioner  
Hanover  
[cpepler@log.on.ca](mailto:cpepler@log.on.ca)

**Meg Reich**

Program Manager  
Geriatric Assessment Program & Mental  
Health Program for Older Adults  
Windsor Regional Hospital  
Windsor  
[gapwrh@wrh.on.ca](mailto:gapwrh@wrh.on.ca)

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Co-chair, Dementia Network of Ottawa  
Vice President  
Planning and Partnerships  
SCO Health Service  
Ottawa  
[bschulman@scohs.on.ca](mailto:bschulman@scohs.on.ca)

**Carol Shaw**

Administrator  
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Coburg  
[gplshaw@phc.ogs.net](mailto:gplshaw@phc.ogs.net)

**Neil Tarswell**

Psychogeriatric Resource Consultant  
Alzheimer Society of Haldimand-Norfolk  
Simcoe  
[tarswell@sympatico.ca](mailto:tarswell@sympatico.ca)

**Don Wackley**

Co-chair  
Ontario Coalition of Senior Citizens'  
Organizations  
Toronto

**Susan King**

Ex Officio  
Program Consultant, Operational Policy Unit  
Ministry of Health and Long-Term Care  
Toronto  
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**Rod Browning**

Ex Officio  
Policy Advisor, Policy Initiatives Branch  
Ontario Seniors' Secretariat  
Toronto  
[roderick.browning@mczcr.gov.on.ca](mailto:roderick.browning@mczcr.gov.on.ca)

## APPENDIX E – Ministry of Health and Long-Term Care Health Care Programs Regional Offices

Peter Finkle, Regional Director  
Ministry of Health and Long-Term Care  
Health Care Programs  
Eastern Region  
10 Rideau St., 8<sup>th</sup> Floor  
Ottawa ON K1N 9J1

Phone Number (613) 364-2253  
**Toll Free** 1-877-779-5559  
Fax Number (613) 569-9670

Jenny Rajaballey, Regional Director  
Ministry of Health and Long-Term Care  
Health Care Programs  
South West Region  
231 Dundas St., Suite 201  
London ON N6A 1H1

Phone Number (519) 675-7654  
**Toll Free** 1-800-663-3775  
Fax Number (519) 675-7685

Michael Klejman, Regional Director  
Ministry of Health and Long-Term Care  
Health Care Programs  
Central East Region  
465 Davis Dr., 3<sup>rd</sup> Floor  
Newmarket ON L3Y 8T2

Phone Number (905) 954-4660  
**Toll Free** 1-800-486-4935  
Fax Number (905) 954-4702

Narendra Shah, Regional Director  
Ministry of Health and Long-Term Care  
Health Care Programs  
Central South Region  
119 King St. West, 11<sup>th</sup> Floor  
Hamilton ON L8P 4Y7

Phone Number (905) 546-8270  
**Toll Free** 1-800-461-7137  
Fax Number (905) 546-8255

Peter Armstrong, Acting Regional Director  
Ministry of Health and Long-Term Care  
Health Care Programs  
Northern Region  
159 Cedar St., 4<sup>th</sup> Floor, Suite 406  
Sudbury ON P3E 6A5

Phone Number (705) 564-7248  
Fax Number (705) 564-7493

Marnie Weber, Regional Director  
Ministry of Health and Long-Term Care  
Health Care Programs  
Central Region Toronto  
5700 Yonge St., 4<sup>th</sup> Floor  
Toronto ON M2M 4K5

Phone Number (416) 327-7115  
Fax Number (416) 327-7763

Michael McEwen, Regional Director  
Ministry of Health and Long-Term Care  
Health Care Programs  
Central West Region  
201 City Centre Dr., Suite 301  
Mississauga ON L5B 2T4

Phone Number (905) 897-4605  
Fax Number (905) 275-7540