

# **Ontario's Strategy for Alzheimer Disease and Related Dementias Initiative #9a Dementia Networks**

## **Report on Regional Information Sessions, Spring 2002**

### **A. Introduction**

Part of the implementation plan for the Dementia Network Initiative was to hold a series of regional information sessions to discuss the creation/enhancement of dementia networks in local communities. The Ministry of Health and Long-Term Care (MOHLTC) Regional Offices were asked to help facilitate these sessions in conjunction with the Dementia Network Work Group.

The Regional Offices were consulted related to the number of meetings required per region, preferred dates for the meetings and the agenda for the meetings. The Regional Office staff in consultation with key stakeholders developed the invitation lists. It was recommended that they consider the full continuum of care when developing their lists. Invitation letters for the sessions were sent from the Regional Directors along with a copy of *A Proposal for the Development of Local Dementia Networks and Support for Ontario's Strategy for Alzheimer Disease and Related Dementias*.

All information sessions included an Update on the Alzheimer Strategy, provided by someone from the government involved in the Strategy, and a presentation by Dr. Ken Le Clair, Chair of the Dementia Network Work Group, providing an overview of Dementia Networks and an introduction to *A Guide to Developing a Dementia Network*. At some of the sessions this was followed by presentations from existing local Dementia Networks and at others there was an opportunity for facilitated small group discussion. The Ministry announced their commitment of providing \$50,000 of seed funding per MOHLTC region to help support the development of dementia networks over the next two years. Evaluation forms were distributed at the end of each session. 350 completed forms were collected and analyzed.

### **B. Summary of Regional Sessions**

#### **Central South**

The meeting was held on March 14, 2002 in Hamilton. There were approximately 50 in attendance covering the four long-term care planning areas (Niagara, Haldimand/Norfolk, Brant, Hamilton). Each of the areas presented on what network activities have occurred to date in their areas.

*Hamilton: (presented by Gertrude Cetinski, Executive Director, Alzheimer Society Halton Wentworth and Chair of the Hamilton Dementia Network)*

Have a local Dementia Network. Used the process of the continuum of care to come up with areas of focus for network activities. Three areas were chosen to focus on:

- To identify dementia services and gaps
  - To produce a guide for families, caregivers --- now would like to put this into a database
  - To look at the impact of changes in the service system network, e.g. CCAC reform
- They are now going to look at new goals for the network and how they will link with the rest of Central South Region.

*Haldimand/Norfolk: (presented by Neil Tarswell, Specialized Geriatric Services of Haldimand/Norfolk)*

Local Geriatric Mental Health Network started ten years ago. Some of the activities have included hosting of Regional Rounds and production of a Geriatric Mental Health Resource Guide (99/00). They are now looking at care mapping and reviewing literature.

*Brant: (presented by Janet Lovekin, Executive Director, Alzheimer Society of Brant)*

Have in place an Interagency group that includes provider agencies, CCAC, LTC facilities, Alzheimer Society, police officer, etc. They have a larger mandate than a dementia network would have and they have a strong educational focus. They are proposing that they form a smaller group from this group to form a local Dementia Network.

*Niagara: (presented by Marge Dempsey, Alzheimer Society of Niagara)*

The Niagara region has had many different committees over the years – the names keep changing but many of the same players are around the table. The Niagara Specialized Services for the Elderly Network was formed primarily as part of the provincial Dementia Networks' Study (Lemieux-Charles & Chambers). This network had met the week prior to this meeting after having not met for one year. At the meeting there was no consensus about focusing on dementia but agreed to meet again after this information session to discuss their commitment to move forward as a dementia network.

*Feedback received at the session:*

- Important to share information among networks
- Plan to have a regional meeting to share information between the 4 local networks
- Need for common goals/concerns between network members
- A quick look at the Guide indicates that it will be very helpful

*Next Steps:*

- There was agreement at the information session to have a Regional meeting with representation from each of the local areas to begin discussion on how the local groups can connect regionally.

## **Central East**

The Central East Region chose to have two regional information sessions due to the size of the region and because there are no existing dementia networks within the region. The first session was held in Peterborough on April 9, 2002, inviting participants from the areas of Durham, Peterborough, Haliburton, Northumberland and Victoria. The second meeting was held on April 12, 2002 in Newmarket with participants from York Region and Simcoe County. There were approximately 70 in attendance at each of the

sessions. At both of the sessions there was an opportunity for facilitated local area discussion.

*Peterborough Discussion:*

*2 discussion groups – Durham and Peterborough/Haliburton/Northumberland/Victoria*

- Examples of collaboration: Durham Regional Health Care Group, CCAC, hospitals, community support service agencies, LTC facilities have come together to address system issues, e.g., Palliative Care Alliance. They have developed integrated services for frail elderly based on this model. Suggestion to build on this approach when looking at a Dementia Network.
- Participants reviewed the existing health networks – in Durham many health networks are in existence that not all participants were aware of
- Importance of practical, workable and measurable outcomes
- It is important to develop a directory of services available in communities
- Sharing of information essential
- Concern expressed regarding sustainability
- Balanced representation (local and sectoral) will help initiate network formation
- Need to look at structures that would work for each local region, e.g. proposed one network for Peterborough, Haliburton, Northumberland and Victoria (HNV) with one coordinating committee and four local task forces.

*Next Steps*

- Review of Terms of References for existing groups, i.e., Frail Elderly Integration Project, to avoid duplication
- Sign-up sheet was distributed for Durham with agreement to meet again
- Determine in Peterborough, HNV who will take on the leadership for moving this initiative forward

*Newmarket Discussion:*

*2 discussion groups for each geographic region of Simcoe and York*

- Discussed existing committees and how the dementia network might link with these, e.g. Simcoe York District Health Council has sponsored a Seniors Health/Dementia Committee for a couple of years with members who represent LTC facilities, CCAC, hospitals, mental health centre, community agencies and consumers
- Participants were receptive to seed feeding and saw dementia networks as a means to maximize resources
- Appreciative of the role of the Psychogeriatric Resource Consultants and the Public Education Coordinators (Alzheimer Societies) in helping to facilitate the development of the Networks
- Challenge to meet, time pressures – essential to have a clear reason to meet
- Need to include caregivers and persons with dementia
- Communication – sharing of information essential
- Consider Network based on subject issues rather than geographic
- Regional versus local model for networking – role of each
- Need to work around political issues of acute care and lack of regional planning
- Do members of the network come as individuals or as representatives of their organizations?

*Next Steps:*

- DHC to look at existing structures – sense of building on existing structures with flexible membership
- Alzheimer Society York Region to share surveys of clients
- Need to look at what exists for seniors
- Next meeting – separate meetings planned for York Region and Simcoe County

## **Toronto**

The meeting was held in Toronto on April 12, 2002 with approximately 90 participants. The presentations and discussion of the Resource Guide were followed by an open discussion.

*Discussion/questions raised:*

- How many networks for Toronto, recognizing that there are presently 2 networks in existence (LINC and GTA Dementia Network for Hospitals)?
- How to build on existing models, e.g., GTA rehab network, Palliative Care Network (4 regional committees and 1 coordinating body), Family Practice Ontario, RGP, CCAC regions (6 CCACs in Toronto)
- A vision is needed – is it a network for GTA or a series of local networks?
- Need for greater level of communication and awareness of existing services
- Need forums that include providers from across the continuum
- What kind of information system would support the network, given the different systems in existence and issues of confidentiality?

*Next Steps:*

- Those in attendance were asked to sign up if they were interested in participating in the development of the dementia network initiative for Toronto
- Dr. Rory Fisher, RGP (sponsoring agency for the Psychogeriatric Resource Consultants in Toronto) and Mary Ann Chang, Alzheimer Society of Toronto agreed that their organizations would help take the lead on facilitating development of the dementia network initiative

## **Central West**

The information session was held on April 16, 2002. There were approximately 50 in attendance from the four areas of Halton, Peel, Waterloo and Wellington-Dufferin. The presentations were followed by facilitated small group discussion.

*Discussion/questions raised:*

- In Waterloo Region – Wellington-Dufferin the DHC have had a group working on identifying gaps and doing service planning – report expected in the fall
- Halton-Peel DHC has also had a group identifying gaps – is this the beginnings of a network?
- Try to have one of the groups in existence as a base – to avoid duplication and to use the resources and work that has already been done or started
- Challenges related to geographic boundaries due to linkages with Toronto and Hamilton

- Think of continuum of care for people and families with dementia to help develop the network
- Need to have clear objectives/reasons to form
- Core leadership must be identified at local level
- Having the Guide to help us get started and to provide some consistency with local flexibility is excellent
- Some concerns regarding funding and sustainability
- Recommended getting together again regionally in 12 to 18 months time to discuss what's working and what is challenging
- Look forward to hearing about network development in other parts of the province

#### *Next Steps:*

- Psychogeriatric Resource Consultants facilitated the sessions and committed to help organizing future meetings within local area
- Four lead agencies were identified and will take first steps to form a dementia network. Peel Region has already held a meeting. Halton Region has a meeting planned.

## **North**

The North hosted two information sessions. The first one was held on April 25, 2002 in Sudbury with video links to Timmins, North Bay and Sault Ste Marie and a total of approximately 50 participants. The second session was held on April 26, 2002 in Thunder Bay with a video link to Kenora and teleconference links to five sites (Geraldton, Manitouwadge, Emo, Ft. Frances, Dryden) with approximately 45 participants. At both sessions there was good representation from across the continuum of care. The presentations were followed by an opportunity for questions and comments. Unfortunately at the session in Thunder Bay the video link connection with the Kenora site was lost during the question period so a follow up meeting was organized on May 13 and Dr. Ken Le Clair and Susan King participated by teleconference.

#### *Discussion/questions raised:*

- "Getting started" is difficult as it is difficult in the North to identify all potential partners and lead agency
- Concern re utilization of the seed funding for the North – high costs of travel
- How does the dementia network link with existing committees, e.g. Memory Assessment Working Group (has local coordinating committee structure in place), or with other networks, e.g. Palliative Care Network?
- Appreciate the role of the Psychogeriatric Resource Consultants in helping to facilitate the development of local Dementia Networks
- Need to understand that in small communities the same person often has to belong to all of the "Networks"
- Need to include caregivers and volunteers in Network – missed on invitation to Information Session

#### *Next Steps:*

- Agreement to plan for future meetings at a local level. Psychogeriatric Resource Consultants agreed to help facilitate organization of meetings.

## East

The meeting was held on May 6, 2002 in Smith Falls. There were approximately 70 participants. The session included presentations from three of the local areas re Dementia Network development and facilitated small group discussions.

### *Eastern Counties: (presentation by Shelly Vaillancourt, Alzheimer Chapter Cornwall)*

The Specialized Geriatric Services Network for the Eastern Counties was established in 2001 under the local hospital and community services alliance and with support from the Champlain District Health Council and the Regional Geriatric Advisory Committee. This Network asked the local Alzheimer Society to take a lead in planning for a Dementia Network. Using the "Guide to Developing Dementia Networks" as well as the "Needs based Planning Approach", a Dementia Network Planning Work Group organized a community planning day on March 22, 2002. The format of the day included presentations on the Alzheimer Strategy and the Ottawa Dementia Network, an introduction of the Psychogeriatric Resource Consultants and the Public Education Coordinator, and break out group discussions to identify client and community needs/gaps/priorities. The goal is to have a Dementia Network in place by 2003. Next steps include the development of task forces, mandates and work plans as well as developing linkages with other networks, including the Ottawa Dementia Network.

### *Ottawa: (presented by Barbara Schulman, Co-Chair of the Dementia Network of Ottawa)*

The Dementia Network of Ottawa was initiated by the SCO Health Service and the Regional Geriatric Assessment Program informally in late 1997. The Dementia Network was then formally launched in February 1999 with no dedicated funding. Structure for the network includes a Steering Committee with co-chairs and 23 members, a Co-ordinating Committee (chairs of the Steering and other committees), and three standing committees (Service Delivery, Education, Research).

Purpose of the Network: To further develop a more coordinated and efficient system for service delivery, education and research related to dementia.

Goals of the Network:

- To develop a more coordinated system of assessment and treatment services
- To address gaps and issues in service provision
- To develop more coordinated educational and information services in the area of dementia for clients, caregivers, referring physicians and agencies
- To develop coordinated research efforts into dementia and associated problems
- To provide a coordinated focus on public policy issues

Discussed accomplishments in service delivery (description of diagnostic assessment and treatment services, local resource guide on driving and resource guide on capacity – in progress), education (Dementia Care Forum 1999, dementia newsletter for family physicians and presentations) and research (Dementia Care Networks' study).

Lessons Learned:

- Need champions
- Need commitment and patience
- Value of information sharing and communication
- Need to focus on concrete achievable goals
- "Open" process

#### Future Challenges:

- develop a continuum of education
- sustainability
- financial resources
- advance the research agenda
- evaluate new structure
- continue to respond to gaps

#### *Southeastern Ontario: (presented by Cheryl O'Connor)*

Meetings have been held in Southeastern Ontario to begin developing both local networks in the six counties and a regional network. Terms of Reference have been drafted and meetings have been held to look at identifying common needs. Discussed a number of shared concerns, e.g., access to diagnosis and treatment, lack of physician education, need for continuous care, resource guide. Leadership to help facilitate the development of local Dementia Networks will be initially provided by the local Alzheimer Societies and the Psychogeriatric Resource Consultants. Over the long term the local networks will choose their appropriate leader/chair. A copy of Draft Terms of Reference shared with the group. The Terms of Reference outline the mandate, goals, leadership, principles, membership, terms of membership, frequency of meetings, location of meetings.

#### *Discussion:*

- Access to services, especially in rural areas is difficult
- Value of communication and awareness of services
- Challenges of information sharing
- Need for inventory of services and a common care plan integrated among partners
- Dementia network to assist in identifying gaps in service and make recommendation for change (locally, regionally and provincially)
- Importance of including caregivers and persons with dementia in networks
- Regional structure required – e.g. two representatives from local level to act as representatives on a Regional network
- Annual meeting of regional group to share ideas
- Relationships between sectors must also be developed locally
- Concerns expressed regarding sustainability

#### *Next Steps:*

- Participants identified the need for support from the MOHLTC regional office and the need for another regional meeting in the fall 2002 once local groups have had the chance to meet and plan

## South West

The information session was held on May 7, 2002 in London with approximately 160 participants. The session included presentations on the Dementia network in London-Middlesex and on SWOGAN (Southwestern Ontario Geriatric Assessment Network) and facilitated discussion in 9 groups at the county level.

### *London-Middlesex: (presented by Dr. Michael Borrie)*

Provided information on one activity of the London-Middlesex Dementia Network – development of a Memory Loss Care Map and Service Provider Guide (handout provided). The group formed after the original consultations were held in 2000 by the Provincial Dementia Network Work Group and they have been waiting for the recommendations from this group before proceeding much further with their development.

### *SWOGAN: (presented by Sharon Mytka, SWOGAN coordinator)*

SWOGAN integrates specialized regional services and local teams to provide more even access to geriatric and psychogeriatric services across SW Ontario. The presentation discussed some of the differences and similarities between SWOGAN and a Dementia Network.

#### Similarities:

- Vehicle to share information
- Committed to the achievement of common goals
- Promote linkages
- Means to do what individual organizations cannot do on their own
- Greater knowledge, skills, coordination and access to individuals in organizations who have ability to address issues across the domains
- Benefit persons with dementia, families and caregivers, providers, health system, and offers a forum for system-wide planning and problem solving
- Focus on the consumer's need
- Member agencies function independently outside the network and may be provincial, regional or local

#### Differences:

- SWOGAN focuses on frail elderly with complex health problems which may include dementia (broader client focus than a Dementia Network)
- SWOGAN teams offer direct service (consultation, education, assessment, networking) – do not represent the full continuum of care

#### Opportunities:

- Established infrastructure/forum for communicating about dementia issues (e.g. website: [www.swogan.ca](http://www.swogan.ca) )
- SWOGAN team cover the SW region
- Geriatric Mental Health resource mapping recently completed
- Many key agencies are members of SWOGAN – seen as a starting point



#### *Discussion:*

- Need for communication regarding services and networks that already exist, e.g., Geriatric Services network exists in Windsor/Essex but was not known by all area participants.
- Need to build on existing structures, i.e. one network with many functions
- Needs assessment of local resources would be helpful
- Need to bring together a broad range of individuals and share information from other areas, e.g., London's Memory Loss Map.
- Inclusion across sectors
- Communication (updates, as well as opportunities for input and feedback) must be maintained throughout the network development process
- Concerns expressed regarding sustainability

#### *Next Steps:*

- Discussed need for district meetings in 6 months to assess progress.
- How to identify structure and link with SWOGAN

### **KEY THEMES**

- Appreciate the Guide – generally viewed as an excellent resource
- Look at existing structures first and then build on these – don't reinvent the wheel
- Need to have clear objectives/reasons to form
- Need for care mapping and identification of services
- Overall need for increasing communication and awareness – development of a network helps foster this
- Must be inclusive across sectors including formal and informal caregivers and persons with dementia
- Start to develop locally but recognize benefit/need to share within the Regions and across the Province
- Appropriate model(s) must address urban and rural challenges
- Appreciative of seed funding but concerned about sustainability
- Core leadership in the first stages will determine long-term outcomes

## **OBSERVATIONS**

- Sessions provided an excellent opportunity to heighten awareness of what others are doing
- Helped regions to identify benefits of networking across the full continuum and to identify who is often missing at other meetings/forums
- Helped clarify and highlight the roles of the Psychogeriatric Resource Consultants and Public Education Coordinators in facilitating the development of dementia networks

## **C. Summary of Results from Evaluation Forms**

The following is a summary of the feedback obtained from the Dementia Network Regional sessions. The information is summarized for each MOHLTC region as well as all regions combined.

### **Number of Feedback Forms Received**

A total of 350 feedback forms were received. The following table summarizes the distribution by region.

<b>Region</b>	<b>Percent (and Number) of Feedback Forms Received</b>
Central East	18.9% (66)
Central West	7.7% (27)
Central South	6.9% (24)
East	11.4% (40)
North	16.3% (57)
Southwest	24.9% (87)
Toronto	12.9% (45)
Missing information re: Region	1.1% (4)
<b>TOTAL</b>	<b>100% (350)</b>

## Understanding of Dementia Networks

*Question: a) Please rate your understanding of dementia networks.  
(1 = "poor"; 2 = "fair"; 3 = "good"; 4 = "very good"; 5 = "excellent")*

Participants were asked to rate their understanding of dementia networks. The overall average was 2.93 or "good". Regional averages ranged from 2.51 to 3.63.

Region	Mean (Std Dev)	Median	Range
Central East	2.89 (.84)	3.00	1 – 4
Central West	3.11 (.81)	3.00	2 – 5
Central South	3.63 (.92)	4.00	1 – 5
East	3.25 (1.0)	3.00	1 – 5
North	2.95 (.95)	3.00	1 – 5
Southwest	2.76 (.96)	3.00	1 – 5
Toronto	2.51 (.94)	2.00	1 - 4
<b>TOTAL</b>	<b>2.93 (.96)</b>	<b>3.00</b>	<b>1 - 5</b>

*b) How does your level of understanding NOW compare with your level of understanding PRIOR to today's session?*

When asked how their level of understanding now compares with their level of understanding prior to the session, the majority of respondents from across the province (72%) indicated that they had a greater level of understanding now. Regional averages ranged from 62.5% to 91.7%.

Region	Less understanding now than before the session	About the Same	Greater understanding now than before the session
Central East (N=66)	0	27.3% (18)	72.7% (48)
Central West (N=27)	0	18.5% (5)	81.5% (22)
Central South (N=24)	0	8.3% (2)	91.7% (22)
East (N=40)	0	32.5% (13)	62.5% (25)
North (N=57)	1.8% (1)	24.6% (14)	73.7% (42)
Southwest (N=87)	0	28.7% (25)	71.3% (62)
Toronto (N=45)	2.2% (1)	33.3% (15)	64.4% (29)
<b>TOTAL (N=350)</b>	<b>0.6% (2)</b>	<b>26.6% (93)</b>	<b>72.3% (253)</b>

\* Percentages are based on the number of cases in each row.

\*\* Totals do not sum to 350 because of missing values.

## Understanding of Support Available Through this Initiative

*Question: Please rate your understanding of the support available through Initiative #9A: Dementia Networks to help create or enhance local dementia networks.*

*(1 = "poor"; 2 = "fair"; 3 = "good"; 4 = "very good"; 5 = "excellent")*

Participants were also asked to rate their understanding of the support available through this initiative to help create or enhance local dementia networks. The overall average rating was 3 or good. Regional averages ranged from 2.56 to 3.67.

Region	Mean (Std Dev)	Median	Range
Central East	2.88 (.84)	3.00	1 – 4
Central West	3.20 (.71)	3.00	2 – 5
Central South	3.67 (.87)	4.00	2 - 5
East	3.36 (.99)	3.00	1 – 5
North	3.08 (.92)	3.00	1 – 5
Southwest	2.90 (.91)	3.00	1 – 5
Toronto	2.56 (.89)	2.00	1 – 5
<b>TOTAL</b>	<b>3.01 (.93)</b>	<b>3.00</b>	<b>1 - 5</b>

## Existing Dementia Networks

*Question: At this time, is there an existing dementia network in your community?*

Region	No	Yes	Sort of	Don't Know
Central East (N=66)	72.7% (48)	16.7% (11)	6.1% (4)	3.0% (2)
Central West (N=27)	63.0% (17)	14.8% (4)	14.8% (4)	3.7% (1)
Central South (N=24)	20.8% (5)	66.7% (16)	12.5% (3)	0
East (N=40)	55.0% (22)	35.0% (14)	10.0% (4)	0
North (N=57)	64.9% (37)	17.5% (10)	8.8% (5)	3.5% (2)
Southwest (N=87)	63.2% (55)	34.5% (30)	1.1% (1)	0
Toronto (N=45)	57.8% (26)	20.0% (9)	2.2% (1)	15.6% (7)
<b>TOTAL (N=350)</b>	<b>60.0% (210)</b>	<b>26.9% (94)</b>	<b>6.3% (22)</b>	<b>3.4% (12)</b>

\* Percentages are based on the number of cases in each row.

\*\* Totals do not sum to 350 because of missing values.

## Information to Share with Dementia Network Work Group

*Question: What information would you like to share with the members of the Work Group for Initiative #9A?*

The following highlights some of the consistent themes found in the responses to this question, as well as specific comments/questions that were addressed to the Work Group.

- Need to build on existing networks / relationships
- Need to have clear objectives/reasons to form
- Involvement of families / caregivers
- Membership should be inclusive of all groups involved in providing care to persons with dementia
- Sharing of information regionally and provincially
- Some help from provincial group to identify and connect potential local champions that may be involved at different levels. (e.g. consumers or physicians in our area that may be on the provincial task groups, have a broader perspective to share)
- Getting together in a year → 18 months to review what's working, what is challenging and review with members of the Work Group
- Maybe discuss the benefits (although obvious) of short-term projects with tangible successes particularly how they will lead to self sustaining networks with an energy of their own - not 'brow beating' to come together.
- Will the networks have support/access to the work group for guidance along the way?
- More guidance on reconciling/balancing - local representation and sectoral representation on 'the prospective network(s)' would be helpful to initiating their formation
- With no one assigned as the lead person or agency it is difficult to get started as to how to best utilize the monies available to develop a dementia network through the North. Suggest for persons willing to be the organizers submit to a central point, then each locality could definite who their players are and who should be involved
- Could this work group share the evaluation of the 4 Dementia networks. What was learned about evaluating networks? What survey questionnaires, focus groups etc. methodologies would be worthwhile repeating/expanding for evaluation of other new developing networks