

Toronto Dementia Network Steering Committee
Minutes of the First Meeting
June 17, 2002, 9:00 a.m.
Toronto District Health Council Boardroom
4141 Yonge Street, Suite 200, North York, ONTARIO

Present:

<i>Dr. Rory Fisher (Co-Chair)</i>	–	<i>Regional Geriatric Program (RGP)</i>
<i>Françoise Hébert (Co-Chair)</i>	–	<i>Alzheimer Society of Toronto (AST)</i>
<i>Chris Dalglish</i>	–	<i>Ontario Long Term Care Association (OLTCA)</i>
<i>Amanda Falotico</i>	–	<i>Ontario Community Support Association (OCSA)</i>
<i>Eric Hong</i>	–	<i>GTA, Hospital Dementia Network (GTA HDN)</i>
<i>Rhona Phillips</i>	–	<i>Ministry of Health & Long Term Care (MOHLTC)</i>
<i>Dr. David Ryan</i>	–	<i>Psychogeriatric Consultant Program (RGP)</i>
<i>Fern Teplitsky</i>	–	<i>Toronto District Health Council (TDHC)</i>
<i>Hindy Wasserman</i>	–	<i>Toronto District Health Council (TDHC) - Guest</i>

Regrets:

<i>Dr. Carole Cohen</i>	–	<i>Dementia LINC (LINC)</i>
<i>Barb Cooney</i>	–	<i>Community Care Access Centre, (CCAC)</i>
<i>Pam Goldsilver</i>	–	<i>Comprehensive Rehabilitation and Mental Health Services (COTA)</i>
<i>Vija Mallia</i>	–	<i>Ontario Assoc. for Non-Profit Homes & Services for Seniors (OANHSS)</i>

1. *Introductions – Dr. Fisher*

The meeting was called to order by Dr. Fisher, who invited those present to introduce themselves. Dr. Fisher then noted that he had been approached by Marlene Weber of the MOHLTC to assist in the development of the Toronto Dementia Network, a component of the Alzheimer Strategy – Initiative #9, and that Françoise Hébert had taken over the Co-Chair position from Mary Ann Chang, recently retired from her position as Executive Director of the Alzheimer Society of Toronto.

2. *Approval of Agenda – Dr. Fisher*

The agenda was approved as presented.

3. *Composition of the Steering Committee*

3.1 Additional members? – Dr. Fisher

The composition of the Steering Committee was reviewed, and additional representation was considered. It was decided to try to involve key organizations and to invite persons who best represent those organizations. Among the groups considered were the Ontario Seniors' Secretariat, COMSOC, the Advocacy Centre for the Elderly, the mental health sector, someone with early stage Alzheimer Disease, a caregiver and a representative on consumers issues.

ACTION: Rhona Phillips will contact the Ontario Seniors' Secretariat for a representative.
Françoise Hébert will invite Karen Henderson of the Caregiver Network.
Additional representation on the Committee will be considered at the next meeting.

3.2 Letter to others who volunteered to serve – F. Hébert

An e-letter will be sent to thank those invited to the Information Session at Providence Centre on April 12, 2002, and also to thank those who volunteered for involvement in the Dementia Network. The Alzheimer Society of Toronto will assume this task and will continue to keep everyone informed, as the Steering Committee will most likely seek everyone's involvement at some point in the future.

4. ***Goal of the Dementia Network and of the Steering Committee – Dr. Fisher***

Dr. Fisher referred to the *Guide to Developing a Dementia Network*, which he suggested was a blueprint for the Committee. He reviewed the Executive Summary goal, purpose and benefits of dementia networks.

F. Hébert added that she hopes a tangible product will result from the work of the Dementia Network, perhaps in the form of a Web site which would gather in one place dementia information of interest to the entire range of stakeholders who provide and use dementia services. She noted that several networks already exist and that there is a need build on rather than duplicate their work.

Discussion. Members felt it crucial that the Dementia Network focus on the person with Alzheimer Disease and the family caregiver as well as on the health and service providers, to create an organized inventory of services for anyone at any level who is looking for information on Alzheimer Disease and Alzheimer services in Toronto. Concerns were expressed regarding the sustainability of this initiative when funding for the Alzheimer Strategy ends. It was noted that this network initiative should try to build on existing networks and services, bringing together in one place disparate but already existing network information.

ACTION: Amanda Falotico will draft a one-page document regarding the 211 community service information telephone number and the blue book. She will investigate possible links to the Dementia Network and will circulate her findings prior to the next meeting.

5. ***Overview of Selected Networks/Initiatives***

5.1 LINC – Dr. Cohen

Presentation rescheduled.

5.2 GTA HDN – Eric Hong

A copy of the GTA Network of Hospital Programs for Dementia Care presentation was distributed, drawn from the GTA HDN Terms of Reference. A Network Information Open House is under consideration, as well as a Staff Exchange Observational Learning Program among member Hospitals. This model could serve as a template for the Toronto Dementia Network.

5.3 TDHC Inventory – F. Teplitsky

A number of projects currently underway by the TDHC were outlined. Most are due to be completed in autumn 2002. Documents (listed in Appendix A) were made available. Findings of the inventory will be discussed at the next meeting.

5.4 Other networks: The Ottawa model, others? – R. Phillips

A snapshot document was distributed, summarizing information about the Caregiver Network, the Caregivers Breakfast Network, Toronto Regional Palliative Care and the Dementia Network of Ottawa. It was noted that the Dementia Network of Ottawa has developed a newsletter for family physicians, as well as a *Driving and Dementia Tool Kit*, which can be found at rgapottawa.com/dementia.

ACTION: Rhona Phillips will contact the Scarborough Dementia Network and any other Toronto networks that come to her attention, and will provide a summary of information to the Steering Committee.

6. *Elements of a Dementia Network Model for Toronto – F. Hébert*

F. Hébert started the discussion by proposing as a project an electronic inventory of the complete range of dementia services in Toronto. The Web site would provide a roadmap of services, for example by organizing information by stages of the disease, with geographic overlay so that services could be highlighted in each area of the city. She suggested that categories of appropriate information could be identified (long term care facilities, day and respite programs, psychogeriatric resources etc...) and that data for the Website could be compiled and maintained by the networks, associations or organizations that represent these sectors. This 'distributed network' model would build on existing resources, adding value to the information by organizing it in one place, and ensuring that the information was kept current by those who are best placed to do so.

Discussion: Lengthy and constructive discussion ensued, with Fern Teplitsky organizing major points on flipcharts. Members felt that some paper-based information may be advisable for groups and individuals who do not use the web. The need for sensitivity was highlighted in light of the linguistic and cultural diversity of Toronto. Bringing together varied information sources would make it possible to identify gaps in service, which could then become the focus of Dementia Networks advocacy initiatives.

It was recognized that goals and objectives of the Toronto Dementia Network need to be developed and adopted before this or any other project initiative can be pursued. Broadly-based goals were discussed. A Delphi process was proposed, in which a *Goals and Objectives* document would be prepared by Fern Teplitsky, Rhona Phillips and the Co-chairs, for distribution to Steering Committee members. Comments would be incorporated into the document which would be re-distributed for a second and perhaps a third round, each round inviting comments and moving closer to a consensus. The consensus document would be submitted for approval at the next meeting of the Steering Committee.

7. *Next steps – Dr. Fisher*

- A list of Steering Committee member names and addresses, plus discussion notes compiled by Fern Teplitsky, will be distributed with the minutes.
- The Alzheimer Society of Toronto will provide secretariat services for the Steering Committee.
- The *Goals and Objectives* document will be developed and distributed in a Delphi Round over the summer months.

ACTION: Fern Teplitsky, Rhona Phillips and the Co-chairs will compile a *Goals and Objectives* document based discussions at the meeting. The document will be distributed in a Delphi Round process over the summer months, looking for consensus prior to the next meeting.

8. *Next meeting – Dr. Fisher*

The next meeting will be at the call of the Co-chairs.

There being no further business the meeting adjourned at 11:30 a.m.

Toronto Dementia Network Steering Committee

June 2002

Dr. Rory Fisher	RGP	Regional Geriatric Program Work: 416-480-6858 Email: rory.fisher@swchsc.on.ca	<i>Co-chair</i>
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Appendix A

Toronto District Health Council

Recent Reports of Interest to the Dementia Network

(available at www.tdhc.org)

Guide to Supportive Housing Services for Seniors in Toronto. Directory. October 2001.

Improving LTC Facility Bed Placement in Toronto. Long Term Care Bed Placement Task Force. Final Report. March 002.

Service Utilization Patterns in Community Care Access Centres in Toronto: 1999 – 2001. Update Report May 2002.

Short-Stay Beds in Long-Term Care Facilities in Toronto. April 2002.

Towards a System of Personal Support & Homemaking Services for Toronto. May 2002.

Toronto Dementia Network Steering Committee

Preliminary Brainstorming – June 17, 2002

Notes Compiled by Fern Teplitsky

Background:

The Ontario Ministry of Health and Long-Term Care (MOHLTC) Alzheimer Strategy includes a requirement (through initiative #9) for all regions across Ontario to develop “networks” to support persons with dementia, their families and caregivers by improving the system of care at the local level.

The Toronto Region of the MOHLTC initiated the formation of a Toronto Dementia Network by inviting over 200 stakeholders to an initial meeting on April 12, 2002. Dr Rory Fisher, Director of the Regional Geriatric Program of Toronto and the Executive Director of the Alzheimer Association (Mary Ann Chang who was recently replaced by Françoise Hébert) were asked to chair the Toronto Dementia Network by the Toronto Region Office of the MOHLTC.

Over 80 people attended the April 12 meeting at Providence Centre and, by their attendance, indicated their interest in being part of the Dementia Network. During the meeting there was enthusiasm in support of the formation of a dementia network in Toronto and by the end of the meeting over 25 people volunteered to work on the development of the Toronto Dementia Network.

Following the meeting an initial Steering Committee (SC) was selected (by the co-chairs and the MOHLTC) from the list of volunteers. Selection was based on organizational/sectoral representation and individuals who were perceived to be “key players” in the area. The inaugural meeting of the initial SC was held on June 17th at the Toronto District Health Council (TDHC).

The following issues were discussed at the meeting:

1. Steering Committee Membership

It was recognized that the SC should represent all stakeholder groups. To date the SC includes a representative from CCACs, OANHSS, OCSA, RGP, PRCP program, TDHC, Dementia LINC, GTA Hospital Dementia Network, OLTC, COTA, and MOHLTC.

The SC questioned the need to add additional members. It was suggested that a consumer or family member, a representative from ACE, a representative from MCSS, and a representative from the Ontario Seniors Secretariat might be added. It was decided that Karen Henderson from the Caregivers Network and a representative from the Ontario Seniors Secretariat would be asked to join the SC.

2. Goal of the Network

It was agreed that the Toronto Dementia Network would work towards improving the support system for people with dementias, their families and their caregivers. The Network will develop a Terms of Reference to reflect this goal.

3. Environmental Scan

Currently there are many dementia / geriatric psychiatry groups and initiatives going on in Toronto. These groups include:

- Mental Health Implementation Task Force – Specialized Services and Seniors Sub-Group,
- GTA Hospital Dementia Network,
- Dementia LINC (Sunnybrooke),
- Scarborough Caregiver Consortium,
- Geriatric Psychiatrists group,
- OCSA Toronto Region,
- Psychogeriatric Resource Consultants Program (PRCP)

4. Membership in the Network

The network will be inclusive and open to all stakeholders – including providers, consumers, family caregivers and the general public. SC members emphasized that it would be important to identify all stakeholder groups, to examine the role that the network could play for each sector, and to ensure that the Network is of benefit to these stakeholders.

5. Optional Approaches to creating a Dementia Network in Toronto

The SC discussed the existence of different networks in Toronto, and how each network operates differently. The different models were explored through a description of several specific networks. It was agreed that additional information on existing networks would be gathered and presented at future meetings.

The SC went on to examine some potential approaches that could be used for the Toronto Dementia Network.

- a. Develop partnerships with existing groups (RGP, Hospital Dementia Network, TDHC Inventory of Geriatric Psychiatry services, LINC/Chain, etc) and have each partner agree to assume responsibility and/or continue responsibility for a particular initiative.
- b. Develop sub groups to share information and discuss issues - on a geographic, linguistic or other basis.
- c. Do an inventory of existing dementia support services and identify gaps in service.
- d. Take an “asset model” approach. That is, look at what we have in Toronto and what we do well, and examine how we can do things better – through partnerships and other strategies.
- e. Identify issues and tasks, and bounce back to stakeholders to determine their interest.
- f. Create awareness of dementia resources amongst Toronto’s different populations and stakeholder groups
- g. Develop a concrete product with the available funds (eg. A database of information and resources, or written resource materials for broad distribution.)
- h. Identify short term goals and concrete positive outcomes.
- i. Be an umbrella/guardian angel to support existing dementia initiatives, facilitating and sharing information between existing groups and activities.

6. Key Issues

The following issues were identified through the brainstorming process:

- **Sustainability:** It will be important to ensure that the Network is sustainable beyond the two-year funded period.
- **Funding:** The Network has limited funding for the implementation period – it will be important to identify ways to secure ongoing funding and to maintain the activities of the network.
- **Value:** The Network will have to prove its value to members so that stakeholders will want to sustain it beyond the start-up period.
- **Information sharing:** It was agreed that, while important, information sharing would not be enough to sustain a network.
- **Finding a niche:** It will be important for the Network to find an appropriate niche and to avoid overlap with existing networks and groups.
- **Information:** It is important to identify, categorize, describe and disseminate information. Information could be organized according to when the information is needed (according to the chronology of the disease and what resources/information is needed at each stage – prevention, assessment, treatment, support.)
- **Accessibility:** Whatever the Network decides to do it is important to consider how accessible the produces may be – to consumers, caregivers, families and providers. (eg. How many people can access the Internet; are resource materials accessible to the lay person; what languages do resources need to be available in; how can information be distributed to consumers, etc.)
- **Best practices:** The Network could have a role in developing, identifying and disseminating best practices and service standards for providers and provider agencies.
- **Toronto's uniqueness:** It was recognized that Toronto is unique in a number of ways – geographically, multi-culturally, socio-economically – and that the network would have to respond to this uniqueness. (A web-based resource might have the capacity to respond to these needs.)
- **Responsiveness:** It was recognized that the Network will need to be responsive to the needs of stakeholders and to Toronto-specific issues (eg. Diversity)
- **Advocacy:** it was suggested that the Network could play a role in advocating for changes to services, programs, etc.
- **Flexibility:** the Network will need to be flexible to respond to members' issues and needs.

7. Follow-up:

The Co-chairs agreed to develop a working document (containing goals, objectives, etc) prior to the next meeting, and to distribute this document to the volunteers who had agreed to work on network development in order to get their input on these directions. A follow-up meeting will be held in September.