



# Toronto Dementia Network

## Dementia Care Needs Assessment Report 2007

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Co-Chairs**

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## About the Toronto Dementia Network

The Toronto Dementia Network was formed in 2002 as part of the *Strategy for Alzheimer Diseases and Related Dementias*. It is an informal partnership that includes all organizations, institutions, agencies and associations in Toronto that provide or have an interest in dementia care. Permanently co-chaired by the Alzheimer Society of Toronto and the Regional Geriatric Program of Toronto, the Toronto Dementia Network is governed by a Steering Committee consisting of leaders in the system of dementia care.

Goals of the Toronto Dementia Network are to:

- 1) foster better communication, information and education in the system of dementia care.
- 2) advocate for better services for persons with dementia and their families.

## Highlights of this Report

This project was conducted to:

- 1) identify the strengths and weaknesses of the current system of dementia care
- 2) recommend improvements
- 3) suggest how to assist the Toronto Central LHIN to improve the system of dementia care.

The Toronto Dementia Network seeks to take an active leadership role in helping to shape the Aging at Home Strategy in order to improve the system of dementia care. A vision for an ideal system of dementia care was developed as part of this project:

*“A comprehensive continuum of care for persons with dementia and their caregivers, that offers flexible access to information, care and support in response to individual need.”*

Our Action Plan consists of the following recommendations, which are fully aligned with the Toronto Central LHIN’s *2007-2010 Integrated Health Service Plan*:

1. Create a Toronto Dementia Network Coordinator position.
2. Build more consistency in services that support people with dementia.
3. Strengthen system navigation services.
4. Develop individual care paths for persons with dementia.
5. Strengthen the relationship between specialized dementia clinics and family doctors.
6. Enhance the Toronto Dementia Network website.
7. Expand the Alzheimer Society’s First Link program.
8. Require initial and continuing dementia education for PSWs and other health disciplines.
9. Design a dementia prevention strategy for brain health.
10. Strengthen the Toronto Dementia Network’s relationship with the Toronto Central LHIN.

The 300 partners of the Toronto Dementia Network are champions for the cause of dementia care, and their commitment, strength and support are essential to actualize the recommendations. The perspective and the voice they represent will help the Toronto Central LHIN to achieve the goals of the *Integrated Health Service Plan* and the *Aging at Home* strategy.

## 1. Purpose of the Project

In 2007, with funding from the Alzheimer Strategy Transition Project, the Toronto Dementia Network retained the FiRM Consulting Team for a Dementia Needs Assessment project to:

- Identify the strengths and weaknesses of the system of dementia care in Toronto
- Recommend ways to improve the system of dementia care
- Strategize on how the Toronto Dementia Network can most effectively assist the Toronto Central LHIN to improve the system of dementia care in Toronto.

The project consisted of an environmental scan to identify issues and trends, 21 interviews and 7 focus groups to advise on the strengths and weaknesses of the current system of care and to describe the attributes of an ideal system, and to provide recommendations on ways that the Toronto Dementia Network can help to achieve the ideal system of dementia care.

## 2. Issues and Trends

Noteworthy are the growing prevalence of dementia and the increasing age and frailty of the caregivers of persons with dementia.

- Toronto projections show 35,854 dementia cases in 2007, growing to 43,446 in ten years, an increase of 21 per cent, a much larger increase than the seniors' population as a whole.
- About half of persons with dementia live at home, cared for by spouses who may themselves be old and frail, or by adult children who must care for their own families in addition to an increasingly debilitated parent. Persons with dementia and their family caregivers need an evolving series of services for an average of ten years after diagnosis.
- Although much progress is being made, Toronto needs better trained family physicians, earlier links to community support services, additional specialized geriatric services, more and better trained personal support workers, increased transportation services and social recreation programs for persons with dementia, and enhanced caregiver support and education.

The Aging at Home Strategy recognizes the urgent need for support services to provide a continuum of care for seniors with dementia, and support for their family caregivers. The Toronto Dementia Network wishes to be an active partner with the Toronto Central LHIN in helping to shape the *Aging at Home Strategy* to improve the system of dementia care.

### 3. The Current State of Dementia Care in Toronto

#### 3.1 System Strengths

Compared to other areas, Toronto is rich in the number and range of dementia services.

- **Primary and specialized care:** Family physicians are key in the early diagnosis and treatment of people with dementia, and the current government focus on primary care is starting to deliver benefits for dementia care, while specialized geriatric services, psychogeriatric resource consultants and outreach teams are valuable components in managing the lengthy continuum of dementia care.
- **First Link to community supports:** As soon as possible after diagnosis, direct referrals by physicians, memory clinics and social service agencies to the Alzheimer Society's First Link program connects persons with dementia and their caregivers to a helpful program of information, referral, counselling and support.
- **Public information:** The public is able to access reliable sources of information about dementia services in Toronto. The Toronto Dementia Network website, for example, lists more than 1,200 distinct dementia services offered by more than 300 organizations in the city. The Toronto Dementia Network and the Toronto Central CCAC are currently discussing how to leverage the strength of this website within the framework of the Toronto Central LHIN's information system.
- **Knowledge, expertise and innovation:** Expertise among dementia service providers leads to the wide dissemination of best practices, excellent resources and useful toolkits. Academic and applied research in dementia is pursued in Toronto by organizations such as Baycrest, Sunnybrook, TRI and the University Health Network, and is disseminated widely and early in Toronto. PIECES, U-First, and the Alzheimer Society's PSW training program are helping to improve front line competence in dementia care. New programs and services such as cluster care and dedicated supportive housing (Ewart Angus House) are making a difference.
- **Lasting Benefits of the Alzheimer Strategy:** The Alzheimer Strategy had a positive impact on the system of dementia care in Toronto. Psychogeriatric resource consultants, public education coordinators, PIECES training and the Toronto Dementia Network are lasting benefits of this Strategy. The newly-announced *Ageing at Home* Strategy offers the opportunity to build on the strengths of the Alzheimer Strategy, for even greater progress in the future.

### **3.2 Service Gaps**

In its 2003 community consultation project, the Toronto Dementia Network found that in spite of many strengths, the dementia care system in Toronto is disjointed, services are unconnected and hours of service often insufficient. Inadequate home care and lack of family counselling trigger premature placement in long term care. There is limited access to culturally appropriate services, and wait times are long for some CCAC services and for geriatric assessments and other specialized geriatric services.

Service gaps in the continuum of care for people with dementias and their caregivers included:

- Lack of public information on preventative practices that can reduce the risk of dementia.
- Insufficient training in recognition and diagnosis for primary care physicians.
- Inadequate referral systems from physicians to community support services.
- Insufficient hours of in-home service to keep people safely at home.
- Lack of support for instrumental activities of daily living for people who live at home.
- Lack of activation programs for people who live at home.
- Lack of behavioural or special care units in long term care.
- Lack of activation or recreation programs for people with dementia in long term care.
- Insufficient hours of personal care for people with dementia in long term care homes.
- Lack of programs and activities for people with early onset dementia.
- Insufficient programs for people who are newly diagnosed or have early stage dementia.
- Insufficient supportive housing services for people with dementia.
- Insufficient respite care to support caregivers of people with dementia.
- Inadequate numbers of nurse practitioners who specialize in geriatric psychiatry.
- Few ethno-specific services.
- Lack of appropriate end-stage care.

### **3.3 Lack of Integration**

Challenges abound in the way services are integrated or coordinated. A consistent problem is the absence of an effective 'system of care' for people with dementia and their caregivers in Toronto, in spite of the array of service providers that deliver good or even outstanding services.

- The case management system is fragmented - everyone is doing some of it but no one has responsibility for individual case management throughout the lengthy course of dementia.
- The referral system is inadequate, as there is limited inter-organizational collaboration to knit services into a continuum of care and to coordinate and deliver services around the needs of the individual client and family. The Toronto Dementia Network plays a role in facilitating communication between service providers, but this role is informal and limited.
- Although changing rapidly because of integration requirements from the LHINs, there is no consistency among organizations in terms of boundaries, service definitions, fees, application processes and eligibility criteria. This leads to confusion on the part of caregivers, and contributes to the overall complexity, inefficiency and disjointedness of the service delivery environment.

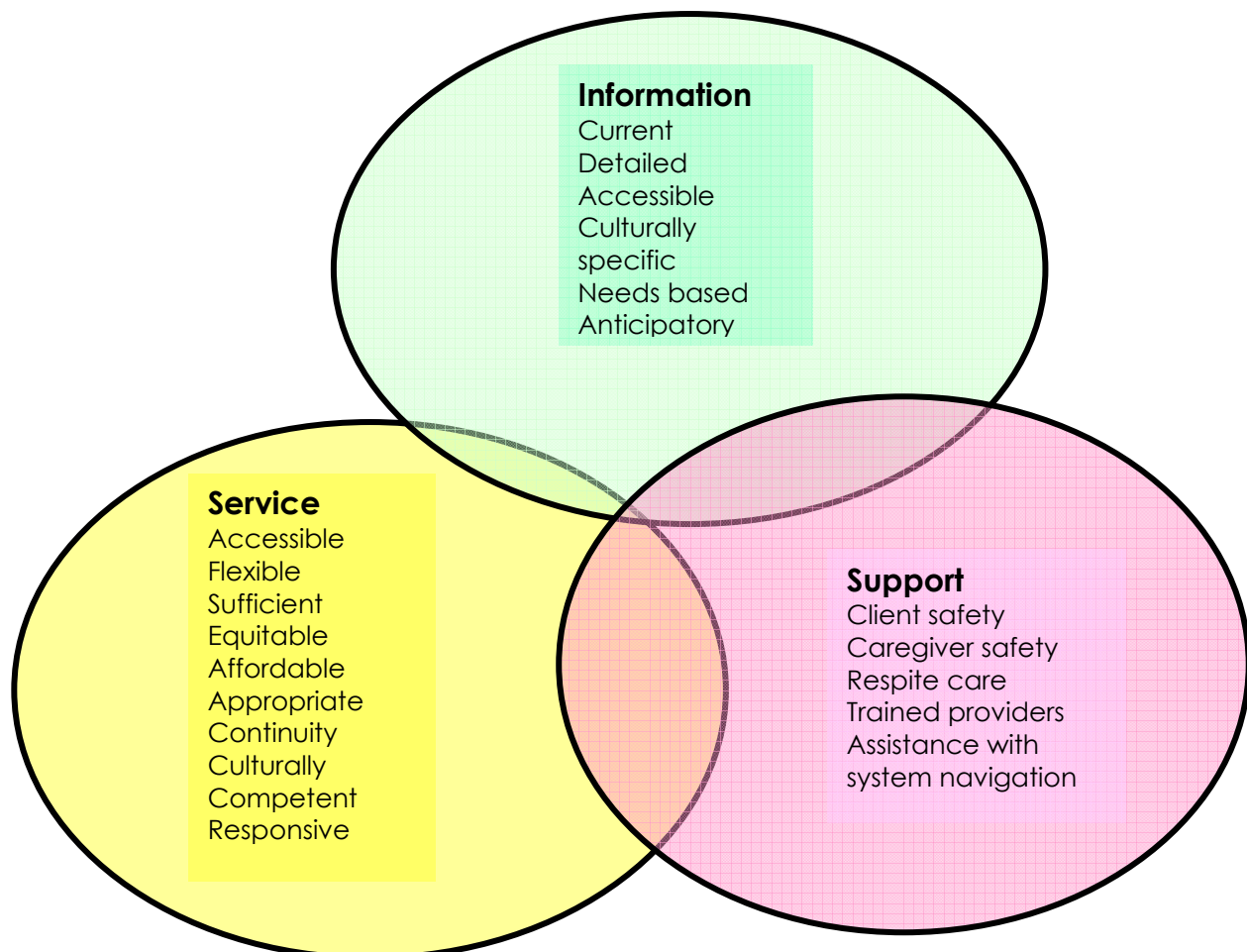
#### 4. Desired Future State of Dementia Care

An expectation of change leading to broadly-based excellence in the delivery of health care was created when LHINs were announced, and the LHINs have taken extraordinary steps to consult with the public and the health care community to define how best to achieve that excellence.

The Toronto Dementia Network has identified a desired future state of dementia care.

- People with dementia should be supported in the community for as long as possible.
- Caregivers should be well supported by the formal health care system, and by service agencies such as the Alzheimer Society.
- Culturally and linguistically specific services should be reasonably accessible.
- Services should be client and family centered, and where possible, client and family directed.
- Information about dementias and about dementia care should be provided to the public at large, as well as to targeted populations of seniors and caregivers of people with dementia.

#### Pillars of an Ideal Dementia Care System in Toronto



#### **4.1 Important services and system attributes**

- Appropriate, sufficient and flexible in-home respite care for caregivers.
- Information, counselling and support for caregivers.
- Easily accessed adult day programs and transportation services.
- Supportive housing services designed for people with dementia.
- Continuing education and training in dementia care in long term care homes and all sectors of the health care continuum.
- Enhanced links between family physicians and community support services.
- Hospital front line workers with skills and sensitivity to care for people with dementia.
- Access to specialized geriatric services as appropriate

#### **4.2 System integration pre-requisites**

- More collaboration between organizations to generate cost efficiencies and improve referrals and transitions.
- Improved coordination in order to build a seamless and transparent system of care.
- Identified system navigators to help clients navigate the health and support systems.
- “No wrong door” when a client tries to access services, so that every door leads to the required information or service.
- A central point of access for information about dementia, dementia services and access to care, based on a current and interactive inventory of services.
- A common and shared assessment process.

#### **4.3 Leadership / planning practices**

The Toronto Dementia Network, alone or in partnership with other groups or organizations, wishes to take a leadership role in setting directions and fostering change to create the desired future state for people with dementias and their caregivers.

- Collaborate with the LHINs in planning for dementia care in Toronto.
- Strengthen the role and relevance of the Toronto Dementia Network.
- Initiate change through leadership.

#### **4.4 Emerging Vision**

A vision for dementia care in Toronto emerged in this project.

*“A comprehensive continuum of care for persons with dementia and their caregivers, that offers flexible access to information, care and support in response to individual need.”*

## 5. Action Plan

The *Toronto Dementia Network Needs Assessment* project highlights a number of key issues and makes several recommendations to improve the system of dementia care in Toronto. Many of these directions echo recent reports from the Alzheimer Society of Ontario and the Alzheimer Strategy Transition Project. That the findings in these two reports parallel each other points to the validity of the issues and recommendations.

### **Recommendation 1: Create a Toronto Dementia Network Coordinator position**

The Toronto Dementia Network needs to be stronger to make a real difference. The Toronto Dementia Network will seek funds from the *Aging at Home* Strategy to hire a full-time coordinator, located at the Alzheimer Society but governed by the Toronto Dementia Network Steering Committee, to support Toronto Dementia Network partners as they develop and work to implement an Action Plan to improve the continuum of dementia care. The Coordinator will identify and document current service-specific gaps in dementia care, and work with the LHIN and with Toronto Dementia Network partners to migrate from the current to the desired state of dementia care.

This recommendation supports the Toronto Central LHIN IHSP Seniors Foundational Activities #3 to build capacity in the community by expanding existing networks, and #4 to determine how best to support existing networks, especially those that support diversity.

The following recommendations could in theory be implemented without a full-time position, but a Coordinator will focus the energies of the 300 partners in the Toronto Dementia Network on priorities that cross the boundaries and interests of their individual organizations. Results will be achieved more quickly and more efficiently if the coordinating function is concentrated in one individual, rather than in the limited volunteer time of Steering Committee members, as is currently the case.

### **Recommendation 2: Build more consistency in services that support people with dementia**

There is considerable variability in eligibility criteria, service boundaries, client fees and client access procedures across different agencies and different programs. We are pleased that community service agencies are taking initial steps to integrate service delivery and harmonize eligibility criteria and access processes. In particular, the Toronto Dementia Network recognizes that adult day programs, meals on wheels, homemaking, in-home respite, and client intervention and assistance, play a vital role in supporting people with dementia, and we want to ensure that system issues are addressed. The Toronto Dementia Network will work with community service agencies to provide the perspective of the person with dementia and the caregiver.

This recommendation supports the Toronto Central LHIN IHSP Seniors Integration Priority #2 to enable seniors to live independently in the community for as long as possible, and the quick win related to No Wrong Door in the *Aging at Home* Strategy.

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**Recommendation 3: Strengthen system navigation services**

The need for system navigation support has been recognized in the Toronto Central LHIN IHSP. There is an urgent need to strengthen the current navigation system for people with dementia and their caregivers, as well as for service providers. System navigation supports must also incorporate the needs of newly diagnosed persons with dementia and their families.

Dementia is a chronic progressive disease and service needs evolve through the course of the illness. There needs to be enhanced understanding of dementia and its impact on the individual and the caregiver. System navigation must be flexible and sustained to assist people with dementia and their families through the full course of health care needs.

The Dementia Network Coordinator would participate in the Toronto Central LHIN Working Group on System Navigation.

This recommendation supports the Toronto Central LHIN IHSP Seniors Action #2 to enable seniors to live independently in the community for as long as possible and Action #4 to pilot the approach to navigate seniors throughout the system.

**Recommendation 4: Develop individual care paths for persons with dementia**

Care paths allow for a standard, best practice approach for patients with a particular disease. A project would investigate the nature and use of care paths in other jurisdictions, and under the guidance of an expert panel of Toronto Dementia Network partners, recommend care paths for persons with dementia.

**Recommendation 5: Develop strategies to strengthen the relationship between specialized dementia clinics and family doctors**

Specialized dementia clinics must be encouraged to work together to clarify admission criteria in order to provide the most equitable access to persons in Toronto, and ensure that family physicians are aware of the role and benefits of the specialized dementia clinics.

**Recommendation 6: Enhance the Toronto Dementia Network website**

The Toronto Dementia Network website is an excellent navigational tool that provides a comprehensive inventory of dementia services in Toronto. It is widely used by family caregivers, referral sources and service providers. The planned LHIN inventory of services should build upon the strengths of the Toronto Dementia Network inventory, not duplicate its listings.

Caregivers may need interactive navigational aids to guide them through a self-help process to identify service options appropriate to their individual situation, thereby lessening their dependence on staff navigators. The Toronto Dementia Network and the Toronto Central CCAC have begun discussions on how to make this happen.

This recommendation supports the Toronto Central LHIN IHSP Seniors Action #1 – Develop an inventory of health-related information, education activities, resources and services for seniors.

### **Recommendation 7: Expand the Alzheimer Society First Link program**

Dr Mittelman's<sup>1</sup> research has demonstrated the long-lasting benefits of counselling for spouses of people with dementia, benefits that far exceed the cost of the initial intervention and that enable them to keep their spouses at home for 557 days longer than those in the control group.

This recommendation builds on the Mittelman's research by expanding the capacity of the First Link program at the Alzheimer Society of Toronto to accommodate more referrals from physicians, memory clinics and social service agencies that encounter persons with dementia and their families soon after diagnosis, and to increase the Society's counselling staff to help persons with dementia and their caregivers to plan for the future and make the most effective use of community services that can help them through the lengthy continuum of the disease.

This recommendation supports the Toronto Central LHIN IHSP Seniors Action #2  
– Enable seniors to live independently in the community for as long as possible.

### **Recommendation 8: Require initial and continuing dementia education for personal service workers and other health disciplines**

This recommendation is in line with the Central Toronto LHIN's Health Human Resource Strategy. It could include PIECES and U-First training for all formal caregivers in residential facilities, hospitals, primary care offices and clinics and a dementia training program targeted to personal support workers hired by families to care for persons with dementia at home, who do not benefit from the team approach of PIECES and U-First.

### **Recommendation 9: A dementia prevention strategy for brain health**

Although the cause of Alzheimer's disease and related dementias is unknown and there is still no cure, research is identifying lifestyle choices that can lower the risk of dementia, and the boomer generation in particular is looking for reliable advice in this area. A multi-pronged project to increase public awareness of dementia prevention strategies would respond to a current need for information and help to lower the future incidence of dementia.

### **Recommendation 10: Strengthen the relationship between the Toronto Dementia Network and the Toronto Central LHIN**

The ideal relationship between the Toronto Dementia Network and the Toronto Central LHIN is one of consultation and partnership. The Toronto Central LHIN's Seniors Council is the natural partner for the Toronto Dementia Network.

- The Seniors Council might wish to appoint the Toronto Dementia Network as a Standing Dementia Working Group to coordinate dementia care, advocate for persons with dementia and their families, and liaise with the Council as appropriate.
- Additionally, the Toronto Dementia Network would welcome a formal channel to the Seniors Council by the appointment of at least one of the members of the Toronto Dementia Network Steering Committee to existing Working Groups such as the System Navigation and Living Independently in the Community groups, who could benefit from the voice and perspective of the community of people living with dementia and their caregivers.

- Ongoing consultation would also be appropriate between the Toronto Dementia Network and the following Toronto Central LHIN Mental Health and Addictions Council, the Back Office Council and the Health Human Resources Council.
- The Toronto Dementia Network recognizes the need to align its initiatives with the Toronto Central LHIN's Integrated Health Services Plan. To this end, the Toronto Dementia Network must:
  - 1) Identify dementia services and resources in the Planning Areas of Toronto Central LHIN
  - 2) Convene meetings of providers in each of the Planning Areas to develop consistent and integrated approaches to dementia service delivery.
  - 3) Keep up-to-date with the development of Charters for each of the Toronto Central LHIN Councils, their overall directions and approaches.
  - 4) Look to what is already being done in the field within the Toronto Central LHIN and build on initiatives already underway wherever possible.
  - 5) Build vertical and/or horizontal partnerships to create a virtual dementia care system in Toronto.

## 6. Next Steps

An objective of this *Dementia Care Needs Assessment 2007* was to initiate a conversation with the Toronto Central LHIN about ways in which the Toronto Dementia Network might work collaboratively with the LHIN to meet the current and future needs of people with dementia and their caregivers in Toronto. This report can inform the LHIN's planning efforts and detail a concrete strategy aimed at improving the integration and coordination of services for people with dementia and their caregivers.

Next steps for the Toronto Dementia Network are to meet with the Board of Directors, staff and Seniors Council of the Toronto Central LHIN, to discuss how to move these recommendations forward. In a parallel process, the Toronto Dementia Network will try to take steps on its own to initiate action on certain recommendations in this report.

The Toronto Dementia Network partners are strong champions for the cause of dementia care. Their strength and support will be needed to actualize the recommendations and action plans contained in this report.

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<sup>1</sup> Mittelman, Mary S. et al. *Improving caregiver well-being delays nursing home placement of patients with Alzheimer disease*. *Neurology* 67, November 2006, p. 1592-1599.

### **FiRM Consulting Team**

- Fern Teplitsky
- Rhona Phillips
- Maria Milanetti

### **Focus Groups**

- Alzheimer Society of Toronto Staff
- Concerned Friends
- Caregivers Breakfast (Front Line Providers)
- Carewatch
- Older Women's Network
- Psychogeriatric Resource Consultants of Toronto
- Toronto Dementia Network Members

### **Key Interviews**

- Catherine Brookman, Ontario Community Support Association
- Cathy Conway, Alzheimer Society of Ontario
- Dr. Carole Cohen, Sunnybrook Health Sciences Centre, Department of Psychiatry
- Stacy Daub, Toronto Central CCAC
- Scott Dudgeon, Alzheimer Canada
- Dollores Elleker, Etobicoke Services for Seniors
- Amanda Falotico, Providence Centre
- Sujata Ganguli, St Clair West Meals on Wheels
- Pam Goldsilver, Community Occupational Therapy Associates
- David Harvey, Alzheimer Society of Ontario
- Françoise Hébert, Ph.D., Alzheimer Society of Toronto
- Lynne Lawrie, Central LHIN
- Dr. Barbara Liu, Regional Geriatric Program of Toronto
- Lisa Manuel, Family Services Association of Toronto
- Carol Millar, Toronto Central CCAC
- Dr. David Ryan, Regional Geriatric Program of Toronto
- Vania Sakelaris, Toronto Central LHIN
- Barbara Schulman, Dementia Network of Ottawa
- Lily Spanjevic, Toronto Rehab Institute
- Andrea Strath, Alzheimer Society of Ontario
- Judith Wahl, Advocacy Centre for the Elderly

## **Members of the Toronto Dementia Network Steering Committee**

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