

**Ministry of Health
and Long-Term Care**

Capacity Planning and Priorities
Branch

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**Ministère de la Santé
et des Soins de longue durée**

Direction de la planification de la
capacité et des priorités

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November 19, 2015

Dear Phyllis Fehr:

As we discussed at the Dementia Strategy Advisory Group meeting on October 20, 2015, the Ministry of Health and Long-Term Care is now forming working groups to bring together leading thinkers, clinical specialists, advocates, people living with dementia and care partners to provide advice to help inform the development of the Dementia Strategy.

The working groups are structured to follow a person's pathway from the early to advanced stages of dementia, along with groups that will address education and prevention, and research and innovation.

We are hoping you are able to participate on the Early Stage Working Group. All meetings will take place in Toronto with a teleconference option. This group is scheduled to meet on the following dates:

1. Monday, December 7, 2015 from 1:00 to 4:00
2. Monday, January 11, 2016 from 1:00 to 4:00
3. Monday, February 8, 2016 from 1:00 to 4:00

In addition to these meetings, we anticipate that there will be some communication by e-mail in order to make the best possible use of the scheduled working group time.

I have attached the terms of reference for the Early Stage Working Group, for your information.

We ask that you kindly confirm your interest in participating by Wednesday, November 25. Please provide your response to Devin Glowinski at devin.glowinski@ontario.ca or 416-212-8165. If you are interested in participating, please provide a short (two or three sentence) description of the perspective that you bring to this group.

Thank you for your contributions to the Advisory Group, and I appreciate your consideration of participating in the Early Stage Working Group. If you have any questions, please feel free to contact me at 416-327-7615.

Yours truly,

A handwritten signature in black ink, appearing to read "Michael Robertson", written over a light grey rectangular background.

Michael Robertson
A/Director

Attachment: Early Stage Working Group Terms of Reference

Mandate

The mandate of the Early Stage Dementia Working Group is to provide advice to ministry staff to aid in the development, communication and implementation of a comprehensive Dementia Strategy (being led by Parliamentary Assistant Indira Naidoo-Harris) for the Province of Ontario. The working group will focus on issues surrounding care during the early stages of dementia.

Background/Context

The development of a Dementia Strategy is a key deliverable of the Ministry of Health and Long-Term Care's (MOHLTCs) *Patients First: Action Plan for Health Care*.

While the province continues to make investments to support people with dementia and their care partners, initiatives are fragmented and based on current needs/demands. A comprehensive and forward looking strategy, rooted in strong long-term planning, is needed to ensure that we are able to meet the current and future needs of Ontarians.

Based on stakeholder engagement to date, a preliminary overview of the vision and guiding principles for Ontario's Dementia Strategy is outlined in the [Appendix](#).

Objectives

The MOHLTC sees the on-going guidance from the Early Stage Dementia Working Group on priorities and process as crucial to the development of a successful Dementia Strategy for Ontario.

The goal of this Working Group is to examine the perceived gaps, challenges, and opportunities related to dementia care service delivery for people living in the early stages of dementia, care partners, as well as health and social care providers. In particular, members of this Working Group will explore various issues in an attempt to delineate some of the underlying mechanisms that may contribute to these challenges and opportunities.

To this end, the Early Stage Dementia Working Group will work collaboratively to:

- Identify population cohorts and unmet needs of people living with early stage dementia and care providers;
- Explore opportunities, best practices, challenges, and gaps related to health and social care service delivery for supporting individuals living with early stage dementia and their care partners; and
- Examine issues surrounding early diagnosis of dementia.

Roles and Responsibilities**Dementia Strategy Advisory Group**

The Objectives of the Early Stage Dementia Working Group will be informed by the Advisory Group.

Early Stage Dementia Working Group Chair

The Early Stage Dementia Working Group will be chaired by and be accountable to Michael Robertson, Director of the Capacity Planning and Priorities Branch (MOHLTC), or delegate. The chair will support the Early Stage Dementia Working Group by facilitating Working Group meeting discussions.

Early Stage Dementia Working Group Members

Members of the Early Stage Dementia Working Group will provide advice to ministry staff by:

- Providing subject matter expertise and participating in discussions to help inform an Ontario Dementia Strategy and its implementation;
- Reviewing information on gaps/needs of people living with early stage dementia; and
- Identifying priority areas for strategy development.

Early Stage Dementia Working Group Ex-Officio Members

Ex-officio members will support the Early Stage Dementia Working Group Members by providing informational resources during meeting discussions.

Capacity Planning and Priorities Branch (MOHLTC)

Capacity Planning and Priorities Branch staff will support the Early Stage Dementia Working Group by:

- Providing coordination, guidance and appropriate inputs to the Working Group; and
- Reviewing feedback and analyzing information discussed during Working Group meetings.

Timelines and Dissolution of the Group

The term of the Early Stage Dementia Working Group will be aligned with the Strategy development process – providing advice to the ministry to initiate, develop and deliver the Strategy.

Working Group meetings will be initiated in Fall 2015 and will be held in person with a pre-arranged teleconference option available. Three meetings are scheduled between December 2015 and February 2016. Additional meetings or opportunities for feedback may be discussed, as required by the Chair, in consultation with Working Group members.

The Early Stage Dementia Working Group shall dissolve at the discretion of the Chair.

Confidentiality and Conflict of Interest**Confidentiality**

Working Group members may have access to confidential information presented to them in the performance of their duties on the Group. Both during and after the term of a members' participation in the Group, members are required to hold in confidence and treat as confidential all information provided or discussed as part of the Strategy development process. All Working Group members will be asked to sign a confidentiality agreement prior to the first meeting.

Conflict of Interest

A conflict of interest arises when a member's private or personal interests may take precedence over or compete with his or her responsibilities as a member of the working group. A conflict of interest may be actual, perceived or potential and may occur before, during and after membership on a working group.

A member of the working group must disclose to the Chair in writing any situation that may be reasonably interpreted as being an actual, perceived or potential conflict of interest.

Group Membership

The Early Stage Dementia Working Group will consist of approximately 20 individuals. Members of the Working Group will have a diverse set of professional and personal experiences. Members may include people living with dementia, care partners of people living with dementia, care providers from various professions (e.g., medicine, nursing, allied health, health system planners) and sectors (e.g., home and community care, primary care, acute care, specialist care, long-term care), as well as researchers.

Amending the Terms of Reference

Potential amendments to the Terms of Reference will be discussed with the Working Group and ultimately approved by the Chair.

Appendix – Preliminary vision and guiding principles for Ontario’s Dementia Strategy

Vision

- All Ontarians with dementia and their families/care partners:
 - Are treated with respect.
 - Have access to information that allows them to make evidence-based choices regarding their health and well-being.
 - Live well with dementia of all causes, assisted by appropriate services and supports where and when needed.

Guiding Principles

- Person-centred models of care which respect the preferences and rights of individuals with dementia, and inclusion of individuals with dementia and their care partners in the strategy development process.
- Education and awareness to reduce the stigma associated with dementia and inform individuals with dementia, care partners and providers on prevention and treatment options and innovations.
- Accessibility and equity of culturally sensitive care across a system that is responsive to both current and emerging needs.
- Comprehensive and coordinated care and supports for individuals with dementia and their care partners facilitated by increased integration and collaboration across the full spectrum of government, services, and sectors.
- Appropriate system capacity across the full continuum of care achieved through evidence-based long-term planning, policy, infrastructure and investment decision-making.
- Accountability and sustainability through ongoing evaluation to ensure outcome achievement and quality.