Mapping the Dementia Journey

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Alzheimer Society of Ontario

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Our Mission: To alleviate the personal and social consequences of Alzheimer's disease and other dementias and to promote research

- Network of 34 local Alzheimer Societies in Ontario
- Member of a national Federation of Alzheimer Societies across Canada
• In Ontario, Canada’s largest province, over 200,000 seniors (one in ten) have dementia

• The number of Ontarians with dementia will increase to 250,000 by 2020; some areas of the province will see increases of more than 35%

**Alzheimer Society core services:**

• Information & education
• Support & counseling
• Public awareness
• Training/education for health-care providers
Programs

**U-First!**

- Training for professional care providers
- Designed for staff in community care, acute care and long-term care

**First Link**

- Referral program that connects people with dementia directly to the Alzheimer Society
- Partners included physicians, other healthcare and community service providers

**Minds in Motion®**

- Community-based physical and mental stimulation program
- Developed in British Columbia
- Being introduced in 12 communities in Ontario over the next two years

**Finding Your Way**

- Offers practical advice to reduce the risk of going missing
- Now offered in eight languages

**Other partnerships:** Behavioural Supports Ontario, Ontario Telehealth
Recent developments in early diagnosis as well as new insights into the social and psychological aspects of late stage dementia all point to the need for updated tools to better equip individuals and families with the necessary information and supports for navigating the dementia journey.

The Alzheimer Society of Ontario is leading a project to “map the dementia journey” in plain language from the perspectives of people with dementia, care partners, and health care providers in Ontario.
Intended Outcomes

• Improve our understanding of the dementia journey through the eyes of people with lived experience

• Include the voices of people with dementia in discussions on research priorities, health system planning and public policy

• Develop new tools and resources to support better person-centred dementia care

• Guide program evaluation, contribute to service design and support advocacy
Focus Group Research

• Three sites across Ontario
• Four groups at each site
  - People with dementia
  - Early stage care partners
  - Later stage care partners
  - Health service providers

Research Team

Elaine Wiersma, PhD, Lakehead University
Sherry Dupuis, PhD, University of Waterloo
Pauline Sameshima, PhD, Lakehead University
Preliminary data analysis

- Combined data from three study sites
- Produced four separate dementia journey maps

Journey Map #1: People with Dementia
**Persons with dementia**

**A Diagnosis**

"It's Like a Bomb": Getting a Diagnosis
- disbelief
- There is no cure
- relief—this has a name
- depression
- feeling sorry for myself
- Why me?
- getting on medications

Doctors don't understand dementia
Doctors are unsupportive

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**Health service providers**

**A Diagnosis**

ALL FORMAL SERVICES ARE CONTINGENT ON A DIAGNOSIS

"Life Takes a Big Turn": Getting a Diagnosis
- Validation and relief
- navigating the system
- can restore a sense of self
- medication

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**Early stage care partners**

**A Diagnosis**

"The End of Life as You Know It": Getting a Diagnosis
- You can't beat it
- Official diagnosis took years, but regular testing showed cognitive decline
- fear of being diagnosed
- frustration in getting a diagnosis

STOP
Interactive stakeholders’ workshop

- 60 participants in downtown Toronto
  - Persons with dementia & caregivers
  - Medical doctors & other health service providers
  - Alzheimer Society staff from across Ontario
  - Alzheimer Association of Greater Michigan and Michigan Alzheimer Disease Center

- Critical discussion of data/journey maps
- Sharing of stories and experiences

“It was a houseful of ideas. Think tank. Encouraged. Thank you”

“This has been humbling, revealing, informative, energetic and inspiring.”
Interactive stakeholders’ workshop

“Being at this session gave me a feeling that I am not alone.”
What have we learned so far?

• Peer support is critical at all points along the journey

• People have critical information needs following diagnosis that are not well addressed – the experience of receiving a diagnosis was described as a ‘black hole’

• There are often differences in the way caregivers and persons with dementia perceive the same things – e.g. In our discussions, care partners expressed more awareness of the future while people with dementia focused more so on ‘the here and now’
What have we learned so far?

- Planning for the maintenance of relationships is essential, and this includes others in the circle of care, such as day program staff and other service providers.

- “The point I can no longer leave him alone” was a critical and very stressful junction in the caregiver’s journey.

- Health service providers believed that ‘best practices’ are out there, but that it is now time to integrate.

“The journey is always evolving & no two journeys are alike!”
Prototype for website
Next steps

- Receive final report from investigators and work with the research team to prepare a peer-reviewed publication
- Pursue more research funding to include voices of
  - different regions – e.g. rural journey
  - other ethnic & socioeconomic groups
- Continue website development & launch
  - linking to programs, resources
  - integrating stories, videos, blogs
- Explore use as an educational tool for primary care
- Identify opportunities for new partnerships
What this means for the work of the Alzheimer Society

• This project is enabling a more person-centred view of the dementia journey

• ASO will use this information to
  – Raise awareness and include the voices of people with dementia in discussions on research priorities, health system planning and public policy
  – Work with local Societies in Ontario to improve & develop programs and services that support our mission
  – Develop new frameworks and approaches with which to organise our information and resources
Thank you!

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Conflict of Interest Disclosure
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- Salary: Alzheimer Society of Ontario