

Mapping the Dementia Journey

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Partnership with Alzheimer Society of Ontario

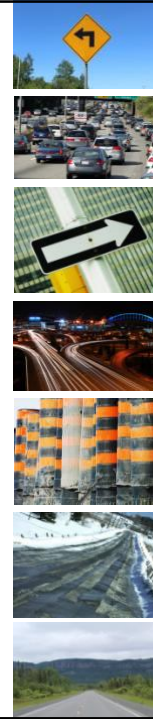
- Funding from Eli Lilly Canada



Alzheimer Society
ONTARIO

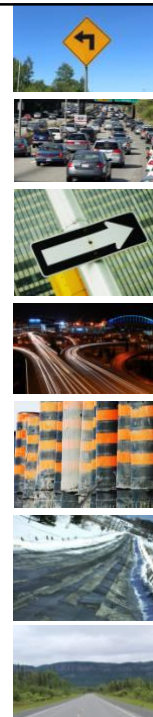
Research Purpose

- To work with **people living with dementia** and **care partners** (including family and health and social service providers) to explore the experiential elements of the dementia journey
- To work collaboratively to **create living "maps" of the dementia journey** that captured key milestones along the way, factors affecting the key milestones, and how these factors influence the journey for individuals, families, and circles of support.



Methodology

- Four separate focus groups in each of the three regions comprised of people living with dementia, care partners early in the dementia journey, care partners later in the journey, and health and social service providers.
- 14 people living with dementia, 21 early care partners, 3 later care partners, and 14 health and social care providers participated in the focus groups.
- A day in November 2013 to bring together key stakeholders and explore the maps



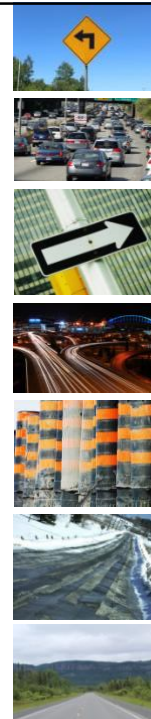


The System Journey

- Testing and assessment [also overlaps with Changing & Adapting]
- Diagnosis [also overlaps with Changing & Adapting]
- Finding out more
- Planning ahead
- Connecting with services
- Giving up driving
- Navigating the system
- Staying at home
- Alternative living arrangements
- Palliative care
- Leaving a legacy

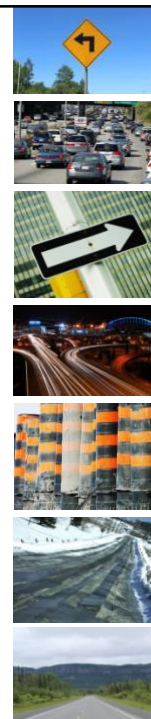
Changing and Adapting

- Crystallizing moments of awareness
- Catalyst
- Diagnosis [described under the System Journey]
- Responding to a diagnosis
- Adjusting to a new normal [also under Caring for Me]
- Reconstructing the future
- Living for today [also under Caring for Me]
- A changing identity [also under Caring for Me and Relationships and Community]



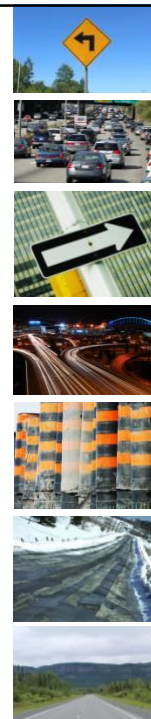
Relationships and Community

- Telling others about the diagnosis
- Changing relationships
- A changing identity [detailed in Changing & Adapting]
- Building circles of support
- Challenging stigma



Caring for Myself

- Keeping a positive attitude
- Coping with emotions, stress, and anxiety
- Adjusting to a new normal [described in Changing & Adapting]
- Living for today [described in Changing & Adapting]
- A changing identity [described in Changing & Adapting]
- Engaging in meaningful activity
- Finding purpose and meaning



MAPPING THE DEMENTIA JOURNEY



Noticing



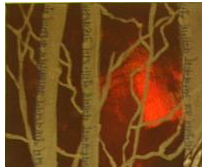
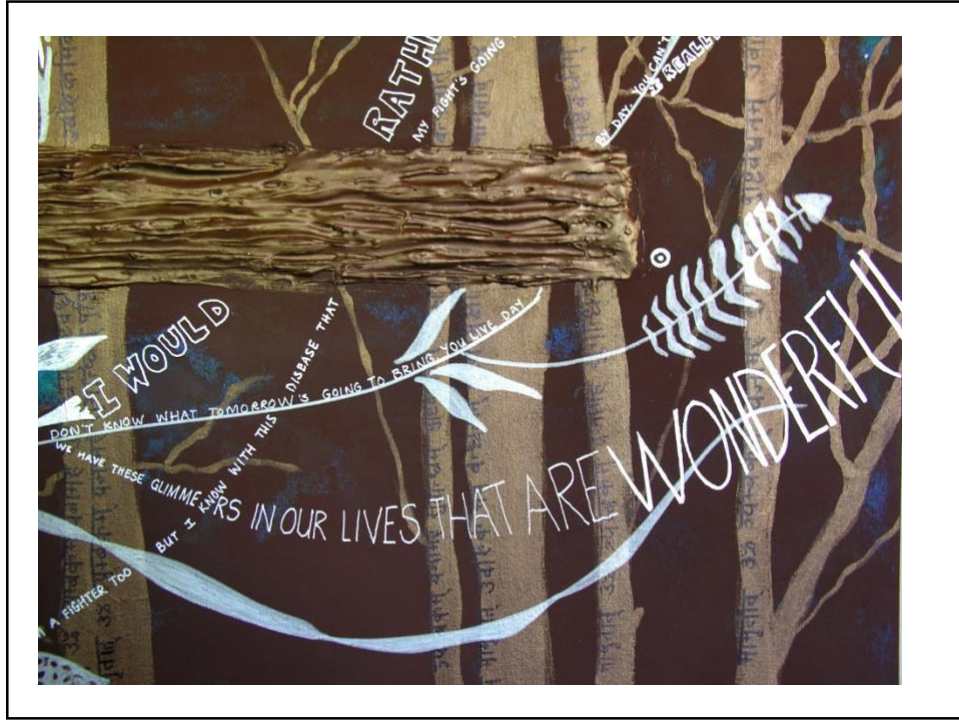
Accepting



Learning



Avoiding



Maha Mrityanjaya Mantra
ॐ त्रियम्बकं यजामहे, सुगन्धिं पुष्टिवर्धनं
उर्वारुकमिव बन्धनान् मृत्योर्माक्षिय मामृतात्

MAPPING THE DEMENTIA JOURNEY



Noticing

Accepting

Learning

Avoiding

With thanks

- Alzheimer Society of Ontario
- Eli Lilly Canada
- People who shared their stories and their journeys

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<http://www.rethinkingdementia.ca/mapping-the-dementia-journey.html>

