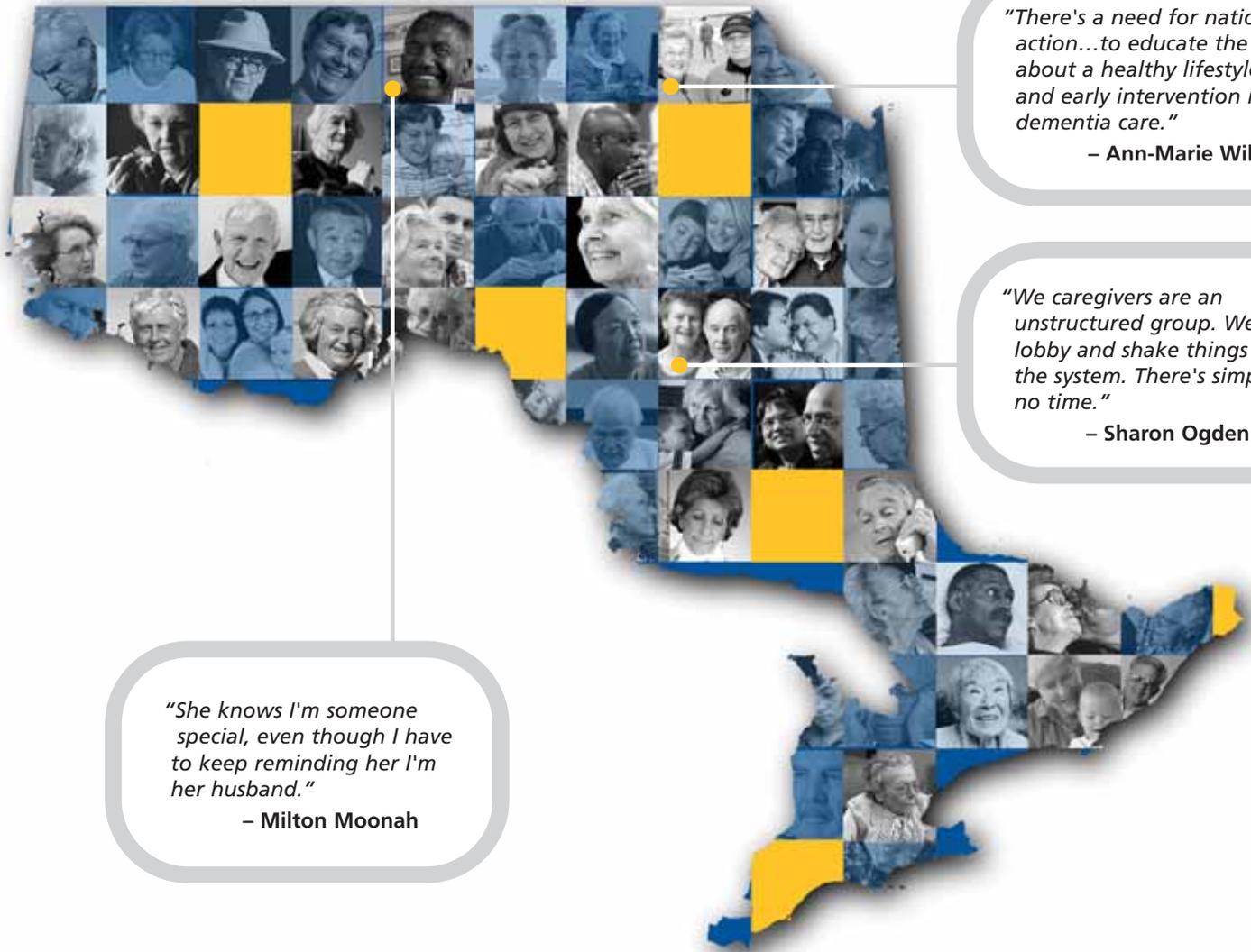


# 10 by 20:

## Ontario action plan for dementia

- Ten action steps by 2020 to prevent dementia, increase the quality of care for Ontario families facing dementia and manage healthcare spending



*"There's a need for national action...to educate the public about a healthy lifestyle and early intervention in dementia care."*

– Ann-Marie Wilson

*"We caregivers are an unstructured group. We can't lobby and shake things up in the system. There's simply no time."*

– Sharon Ogden

*"She knows I'm someone special, even though I have to keep reminding her I'm her husband."*

– Milton Moonah

# Ontarians meeting the dementia challenge

Hearing a doctor tell you that you have dementia is frightening. Seeing someone you love struggle to speak, lose the ability to get dressed or eat, and eventually be unable to recognize even a beloved child is frustrating and painful. Being forced to leave your job to care for someone with dementia has a devastating impact on the entire family, as well as the Ontario economy.

As Ontario's population ages, hope lies in finding ways to lessen dementia's crippling effect on families, the health care system and the economy. Educating people about the value of a healthy lifestyle in preventing or delaying dementia is critical. Much work needs to be done on the health care and community support systems through which people will receive care and help. The influx of financial, legal and policy issues that dementia poses must be addressed.

Investing now in better prevention, better care and better support will pay off later. Dementia planning isn't just good social policy. It makes economic sense. The time to act is now.



**Ruth Simmons, Hamilton**

Ruth Simmons, 75, looks after her husband Ted day and night, other than a few hours a week when Ted is at a program.



**Amanda Wootton, Timmins**

Early onset Alzheimer's runs in Amanda Wootton's family. Her mother died of it at 46. Amanda has tested positive for the defective gene. Now, her son Sheldon also has a 50-50 chance of developing the disease.



**John Campbell, Toronto**

Twice daily, John Campbell, 82, visits his wife Nora in her long-term care home. With no children and little family, John is Nora's sole visitor. Belonging to an Alzheimer Society support group helps, but John often feels lonely and overwhelmed.

*"What is required is a systematic societal approach toward the management of dementia, integrating all levels of caregiving, from physician to caregiver support, and patient services..."*

**Dr. Sandra Black**, Director of the Neurosciences Research Program at Sunnybrook Research Institute in Toronto.

*"Our politicians need expert help in dealing with the costs of aging."*

**Jeffrey Simpson**, The Globe and Mail, February 2

*"The diagnosis of Alzheimer's disease was a shock. I thought it was an old person's disease. I was 60."*

**Mary McKinlay**

# 10 by 20: Ontario action plan for dementia

(Chart continued next page)

## Outcomes

*Our solutions would mean **reduced economic and social burden of dementia** through*

- Healthy lifestyles that help prevent dementia
- More people seeking early diagnosis and intervention
- Improved capacity for people with dementia to live well, with dignity
- Increased knowledge about dementia
- Skilled and seamless dementia workforce
- Integrated care delivery

## What is dementia?

The term “dementia” is used to describe symptoms that occur when the brain is damaged by diseases and conditions such as Alzheimer's disease or vascular dementia. As yet, most forms of dementia cannot be cured.

## Challenges

### Ontario government has led the way...

- The 1999-2004 Alzheimer Strategy was the first of its kind in Canada; the time is right for a renewed commitment
- Aging at Home Strategy promises more community supports
- Local Health Integration Networks make local funding decisions based on local needs
- Family Health Teams and nurse-led clinics increase service
- Behavioural Support Systems project promises breakthrough services for this high-need sub-group

### Yet challenges must be met across the health service system

All Local Health Integration Networks (LHINs) show dramatic increases in people with dementia, yet...

- Only 5 LHINS have specifically included dementia in their plans for elder care
- No system-wide training has ever been supported

The Aging at Home Strategy helps seniors live independently and 17% of home care clients have dementia, yet...

- The Strategy does not identify dementia as a priority
- Fewer Community Care Access Centres have special “dementia teams” than 5 years ago
- Family caregivers report stress levels 3 times greater than those caring for people with other chronic diseases

Ontario hospitals are suited for acute care, yet...

- 25% of patients in Ontario hospitals who remain there too long have dementia

65% or more of residents in Ontario's long term care homes have dementia, yet...

- No new recent investment in dementia training has been made

# 10 by 20: Ontario action plan for dementia

(Chart continued from previous page)

## Solutions: Our ten-step plan

### Brain health, early diagnosis and intervention

1. Launch a public education campaign to overcome stigma, foster supportive communities, facilitate early diagnosis and encourage brain-healthy lifestyles
2. Enable early diagnosis and intervention through accessible primary services integrated with community supports via First Link\*

### Caregiver support

3. Increase access to community, respite care and home support services that use best practices in dementia care
4. Introduce flexible workplace policies and income supports for family caregivers

### Dementia workforce

5. Strengthen skills through more dementia-specific training across the health and social service sector
6. Increase accessibility to specialized geriatric services

### Research

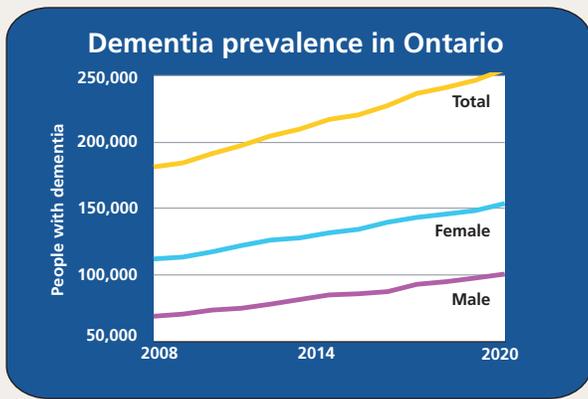
7. Invest in interdisciplinary research and accelerate findings into practice
8. Partner with private sector to foster innovation in areas such as housing and assistive technology

### Champions for change

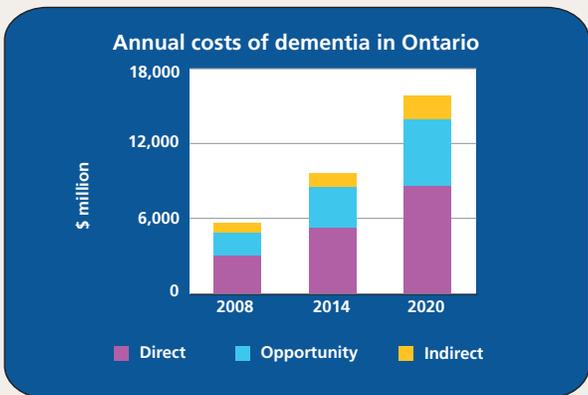
9. Establish dementia as a priority in Ontario government policies
10. Lead the charge in making dementia a national priority

\*See back panel

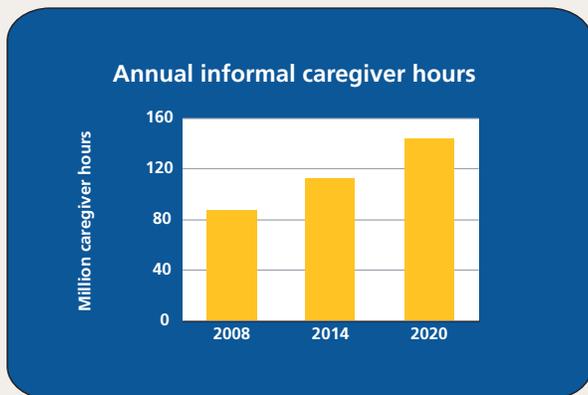
# Dementia by the numbers



Today, 181,000 Ontarians have dementia, a number that is expected to rise 40% to 255,000 by 2020, ten short years away.



The annual total economic burden (including direct, indirect and opportunity costs) of dementia in Ontario is expected to increase by more than \$770 million per year through 2020.\*



Today, families and friends spend 87.1 million unpaid hours caring for people with dementia. By 2020, they'll be offering 144 million hours, an increase of 65%.

\* Costs include the direct costs of health care services, the opportunity costs of caregiving's impact on the ability to work, and the indirect costs of lost productivity and lost wages.

**Dementia prevalence in Local Health Integration Networks (LHINS)**

|   | 2008   | 2016   | % Increase |
|---|--------|--------|------------|
| LHIN 1 - Erie St. Clair                   | 9,000  | 10,600 | 18         |
| LHIN 2 - South West                       | 14,200 | 16,800 | 18         |
| LHIN 3 - Waterloo Wellington              | 8,500  | 10,900 | 28         |
| LHIN 4 - Hamilton Niagara Haldimand Brant | 21,500 | 25,800 | 20         |
| LHIN 5 - Central West                     | 6,600  | 9,400  | 42         |
| LHIN 6 - Mississauga Halton               | 10,500 | 14,800 | 41         |
| LHIN 7 - Toronto Central                  | 16,200 | 18,700 | 15         |
| LHIN 8 - Central                          | 18,400 | 24,900 | 35         |
| LHIN 9 - Central East                     | 20,100 | 25,300 | 26         |
| LHIN 10 - South East                      | 7,800  | 9,200  | 18         |
| LHIN 11 - Champlain                       | 15,500 | 19,200 | 24         |
| LHIN 12 - North Simcoe Muskoka            | 6,000  | 8,200  | 37         |
| LHIN 13 - North East                      | 8,100  | 9,800  | 21         |
| LHIN 14 - North West                      | 3,100  | 3,500  | 13         |

- All LHINS show an increase in dementia prevalence, ranging from 13% to a compelling 42% spike.

Projected Prevalence of Dementia: Ontario's Local Health Integration Networks, Alzheimer Society Ontario, 2007

## Ontario speaks

In November 2009, the Alzheimer Society asked Ontarians with dementia, their caregivers and professional service providers about dementia services in Ontario. Here's what they said:

- 93% believe that the range of care and support services in Ontario needs to be improved.
- They rank early diagnosis as the greatest benefit to people with dementia and caregivers.
- 62% name direct payments and tax credits as the most effective way to ease the financial burden of caregiving.
- 75% rank access to specialists and collaboration between healthcare practitioners as having the greatest impact on people with dementia.

# Alzheimer Society of Ontario

Help for Today... *Hope for Tomorrow*

The Alzheimer Society of Ontario is the leading care and research charity supporting people living with dementia.

## Early diagnosis and support

A province-wide network of 39 Chapters provides community services such as individual and family counselling, education and information, support groups, respite care and day programs. Charitable donations and the Ministry of Health and Long-Term Care support many of these services.

\*First Link, a model service for early intervention developed by the Alzheimer Society, quickly connects newly diagnosed individuals with community health and social services. The program has expanded from 9 to 26 communities in 3 years, thanks to a \$2.4M investment through Ontario's Aging at Home Strategy.

## Community collaboration

We work with other health organizations to increase public awareness, champion positive public policies for people with dementia, and offer dementia education and training to health care providers throughout the province. Partners include the Ontario Neurological Health Charities, the Ontario Caregiver Coalition, of which the Society is a lead member, and the Ontario Dementia Network.

The Alzheimer Society of Ontario is the managing partner in the Alzheimer Knowledge Exchange, a virtual network partially supported by the Ontario government, that disseminates new knowledge and fosters communities of learning among people in the dementia field.

## Finding a cure

Alzheimer Societies in Ontario are key contributors to the Alzheimer Society National Research Program, a collaborative effort between the Alzheimer Society of Canada (ASC), its provincial affiliates, partners and donors.

ASO is also a co-founder and lead funder (\$12M to date) of the world-renowned Centre for Research in Neurodegenerative Diseases (CRND) at the University of Toronto.

## How you can help

Learn how you can help Ontario prepare for the rising tide of dementia.  
Visit [www.alzheimerontario.org](http://www.alzheimerontario.org)

This report is based on *Rising Tide: The Impact of Dementia on Canadian Society*, a study commissioned by the Alzheimer Society of Canada, released in January 2010. The full report is available at [www.alzheimer.ca](http://www.alzheimer.ca).

**Alzheimer Society**  
O N T A R I O

20 Eglinton Avenue West, Suite 1600, Toronto, Ontario M4R 1K8  
Tel: (416) 967-5900 • Toll Free: 1-800-879-4226 • Fax: (416) 967-3826  
E-mail: [staff@alzheimeront.org](mailto:staff@alzheimeront.org) • Web: [www.alzheimerontario.org](http://www.alzheimerontario.org)

