Dementia Evidence Brief:

Waterloo Wellington Local Health Integration Network
July 2012

Alzheimer Society
ONTARIO

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Introduction

Dementia is a brain disorder characterized by impaired cognitive functioning that can affect learning and memory, mood and behaviour, as well as the ability to conduct daily activities and high level functions such as management of other chronic conditions.

Degenerative brain illnesses, such as Alzheimer's disease, vascular dementia, frontotemporal lobe dementia and Lewy body disease, lead to irreversible forms of dementia that are progressive and shorten life expectancy. To date, there is no known cure or effective means by which to delay onset or progression. The median time of survival for Alzheimer's disease (which accounts for 60-70% of dementia cases) has been estimated at 7 years.[1]

Most experts agree that a certain amount of cognitive decline can be expected with normal aging. However, it is important to emphasize that dementia is not a part of normal aging; it is a chronic, progressive and ultimately fatal disease. While the risk for dementia does increase with age, an estimated 2-10% of all cases actually start before the age of 65.[2]

This year, the World Health Organization has declared dementia to be a "Public Health Priority" on a worldwide scale. The following document is intended to demonstrate the epidemiological evidence of the growth of dementia and its projected impact on Ontario's health system at a regional level. As the most reliable dementia prevalence rates have been generated in studies of people over the age of 65, this report will focus its attention on seniors.

As part of the mandate of the Integrated Health Service Plans (IHSP) is to consider major trends and respond at a local level, we are urging the local LHINs to adopt an integrated care strategy that encompasses major chronic conditions and acknowledges the significant cumulative impact of dementia.

The burden of dementia can no longer be overlooked.

[1,2] World Health Organization, 2012, Dementia: A Public Health Priority

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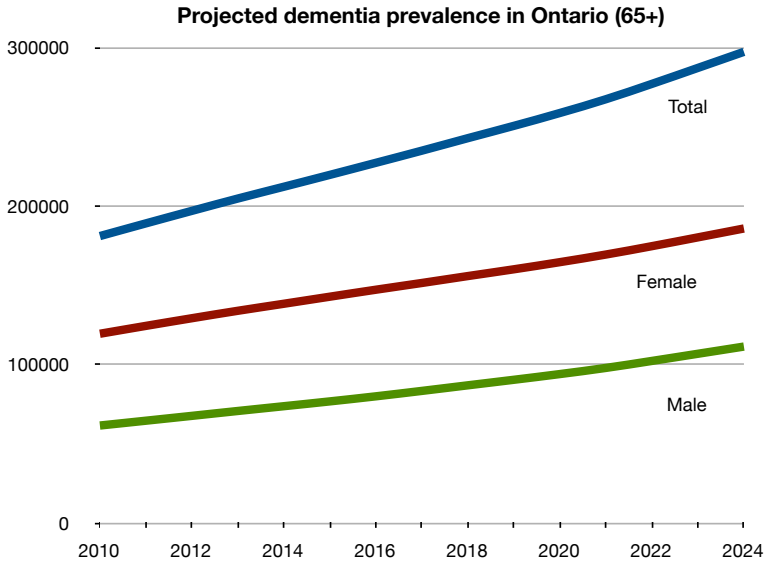
Dementia is a core issue impacting Ontario's health & social system

> *Our society now confronts a growing phenomenon – that of a burgeoning aging population of individuals living with frailty and/or multiple co-morbidities, all of which may be confounded by the challenges of dementia.*[3]
>
> Dr. David Walker, Provincial ALC Lead, 2011

As the Baby Boomer population ages, the number of seniors with dementia is expected to increase dramatically. Nearly 200,000 Ontarians over the age of 65—or one out of ten—are now living with this disease, an increase of 16% over the past four years. By 2020, close to one quarter of a million seniors in Ontario will be living with dementia.[4]

Figure 1.



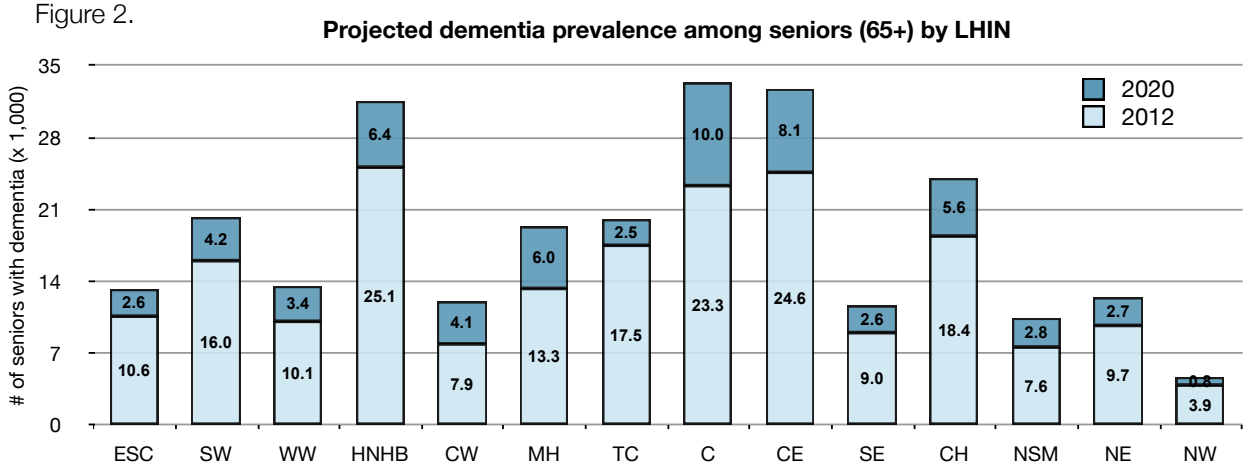
[3] D. Walker. Caring for Our Aging Population and Addressing Alternate Level of Care, Report Submitted to the Minister of Health and Long-Term Care, 2011.

[4] Dementia prevalence was calculated using 2006 Census-based Ministry of Finance Population Estimates (2001-2010) & Projections (2011-2036) for Local Health Integration Networks (unpublished, updated May 2011) and prevalence rates from the Alzheimer Society of Ontario, "Projected Prevalence of Dementia: Ontario's Local Health Integration Networks," April 2007 (based on the Canadian Study of Health and Aging, 1994).

The effects across Ontario's health-care system

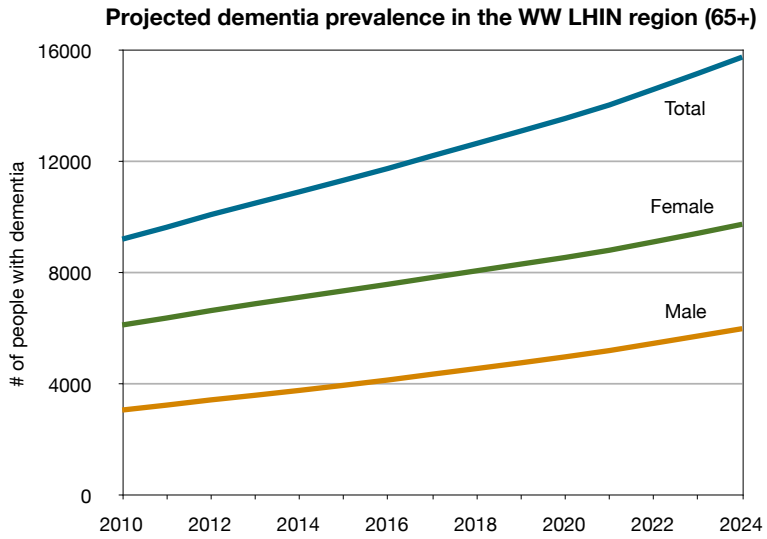
Increases in dementia prevalence will vary among different regions in Ontario depending on the demographics of its population. As age is a primary risk factor for dementia,[5] those regions expecting substantial increases in the number of people aged 80 and above will experience the highest growth in dementia prevalence.[6]

Figure 2.



Today, more than 10,000 people over the age of 65 in the Waterloo Wellington LHIN region are living with dementia. Between 2012 and 2020, the total number of seniors with dementia in the region is expected to increase by 34% to more than 13,500 people. Increases in the number of

Figure 3.

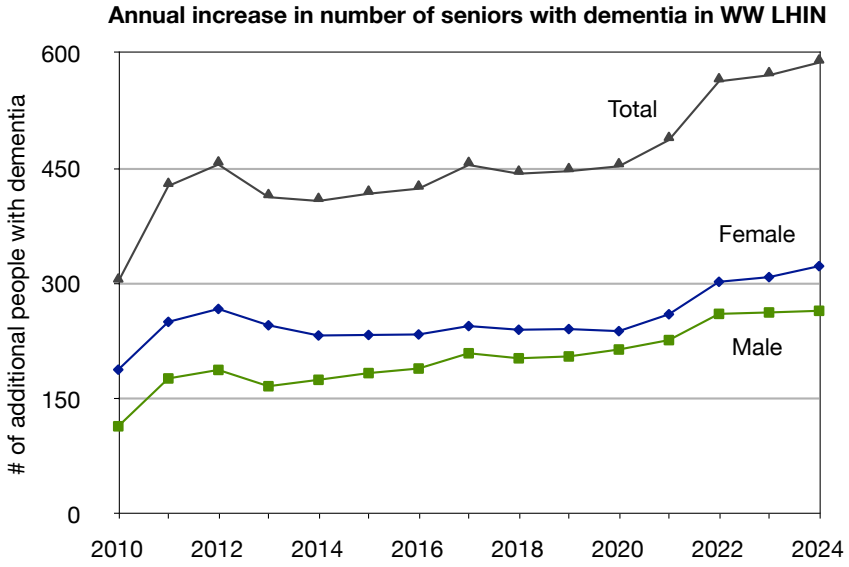


[5] Daviglus et al. Archives of Neurology, 2011, 68(9):1185-1190.

[6] Ontario LHINs: Erie St. Clair (ESC), South West (SW), Waterloo Wellington (WW), Hamilton Niagara Haldimand Brant (HNHB), Central West (CW), Mississauga Halton (MH), Toronto Central (TC), Central (C), Central East (CE), South East (SE), Champlain (CH), North Simcoe Muskoka (NSM), North East (NE), North West (NW)

people with dementia will intensify already existing strains on community care resources, emergency departments (ED) and acute care hospitals.

Figure 4.



People with dementia are at high risk for complexity and hospitalization.

In Ontario, greater than 90% of community-dwelling seniors with dementia are living with two or more coexisting chronic medical conditions.[7] People with dementia face extraordinary challenges self-managing their general health and chronic conditions (e.g., diabetes, coronary artery disease, heart failure, chronic pulmonary disease, etc.) due to problems with memory, perception of symptoms, decision-making and expressive language.[8] As a result, potentially treatable conditions become exacerbated in the presence of dementia.

People with dementia are prone to cycles of emergency department-use and hospitalization, stabilization, discharge to home, poor self-management, deterioration, and readmission to the hospital.[9] The destabilization of other chronic diseases leading to complexity and avoidable hospitalizations has been called “the dementia domino effect.”

Individuals with dementia are also at a heightened risk for delirium and functional impairments in response to acute illness.[10] Recovery from delirium is often slow and sometimes incomplete, resulting in long hospital stays, alternate level of care days, or premature LTC placement.

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[7] Gill, et al. Health System Use by Frail Ontario Seniors, Institute for Clinical Evaluative Sciences, 2011.

[8] Phelan et al. Journal of the American Medical Association, 2012, 307(2):165-172.

[9] Report of the Standing Committee on Health, Chronic Diseases Related to Aging and Health Promotion and Disease Prevention, May 2012.

[10] Phelan, op. cit.

Research in Ontario shows that seniors with dementia are intensive users of health-care resources.[11] **People with dementia are**

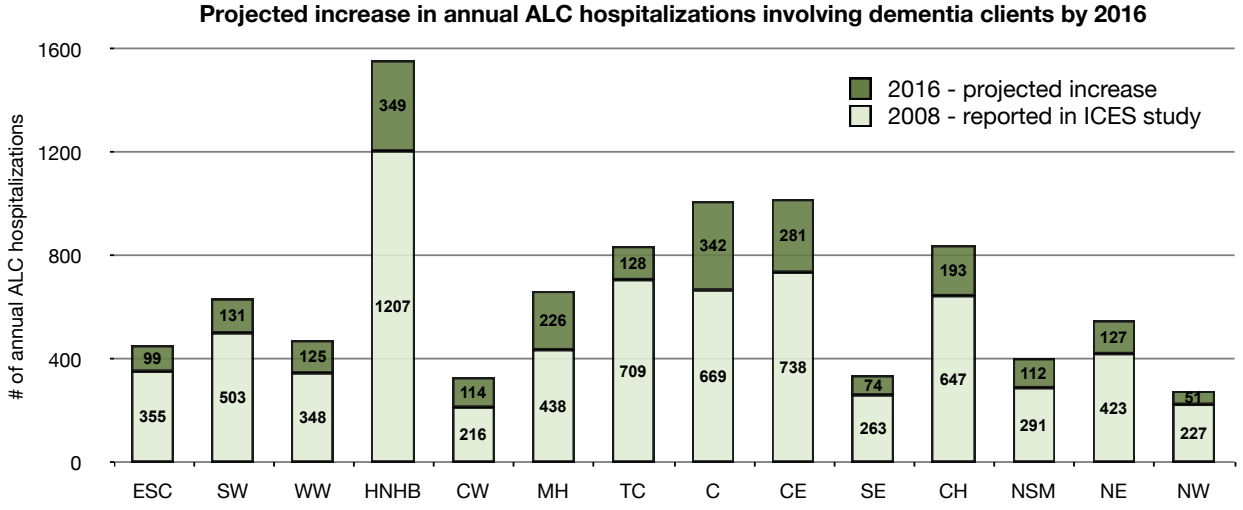
- Twice as likely to be hospitalized compared to seniors without the disease
- Twice as likely to visit emergency departments for potentially preventable conditions
- More than twice as likely to have alternate level of care days when hospitalized
- Nearly three times more likely to experience fall-related emergency room visits

"Dementia is the key diagnosis" related to hospitalizations with ALC days.[12]

The term "alternate level of care" (ALC) describes the use of hospital beds by patients who no longer require acute care services and are waiting for transfer to more appropriate settings, such as residential care or rehabilitation. The Canadian Institute for Health Information has determined that one out of four Canadian seniors hospitalized with ALC days in 2009/10 had a diagnosis of dementia. Moreover, hospital stays involving clients with dementia were twice as long on average (median, 20 versus 9 days) than for seniors without the disease.[13]

In a recent study, the Institute for Clinical Evaluative Sciences indicated that in 2008 the Waterloo Wellington LHIN had 348 ALC hospitalizations involving community-dwelling older adults with dementia.[14] Without improved dementia care, the number of ALC hospitalizations involving seniors with dementia is expected to grow in proportion to the increase in dementia

Figure 5.



[11] Gill, op. cit.

[12] Wait Time Alliance, 2012, Shedding Light on Canadians' Total Wait for Care: Report Card on Wait Times in Canada.

[13] Canadian Institute for Health Information, Health Care in Canada, 2011: A Focus on Seniors and Aging.

[14] Ho, et al., Health System Use by Frail Ontario Seniors, Institute for Clinical Evaluative Sciences, 2011.

prevalence. By 2016, the total number of ALC hospitalizations involving seniors with dementia in the Waterloo Wellington region could surpass 470 per year.

"Acute care hospital bed gridlock" will continue until dementia is recognized as a central part of the ALC crisis and effective strategies focusing on dementia are put into practice.

The effects on Ontario's families and caregivers

According to Ontario home care assessments, most people with dementia have at least one individual providing unpaid care.[15] Primary caregivers are most often spouses or adult children and in-laws. In addition, friends, neighbors or other relatives also contribute time and resources to caregiving.

The care needs of people with dementia will increase significantly as the disease progresses. Cognitive decline and intensifying functional impairments result in greater needs for assistance with basic activities of daily living. In the later stages of dementia, estimates of total care hours contributed by family and friends can range from seven to fifteen hours per day.[16]

Yet, "high-needs seniors receive, at most, a few more hours of home care per week than those with moderate needs."[17] In some cases, seniors with high needs actually receive fewer care hours.[18] The additional care is contributed by friends and family.

Evidence shows that people caring for someone with dementia

- Provide 75% more care hours than other caregivers[19]
- Report feelings of distress, anger or depression, or inability to continue care – in one out of five cases[20]

A recent Canadian Institute for Health Information study determined that rates of caregiver distress were five times greater among individuals caring for seniors with moderate to severe cognitive impairment—likely resulting from Alzheimer's disease or other forms of dementia—compared to individuals caring for seniors without cognitive impairments.[21]

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[15] Gill, op. cit.

[16] Davis et al. International Journal of Geriatric Psychiatry, 1997,12: 978-988.

[17] Health Council of Canada, April 2012, Seniors in need, caregivers in distress: What are the home care priorities for seniors in Canada?

[18] Sinclair et al. Turning a private trouble into a public issue, Alzheimer Society of Ontario, 2010.

[19] Health Council of Canada, April 2012, Seniors in need, caregivers in distress: What are the home care priorities for seniors in Canada?

[20] Gill, op. cit.

[21] Canadian Institute for Health Information, August 2010, Supporting Informal Caregivers—The Heart of Home Care

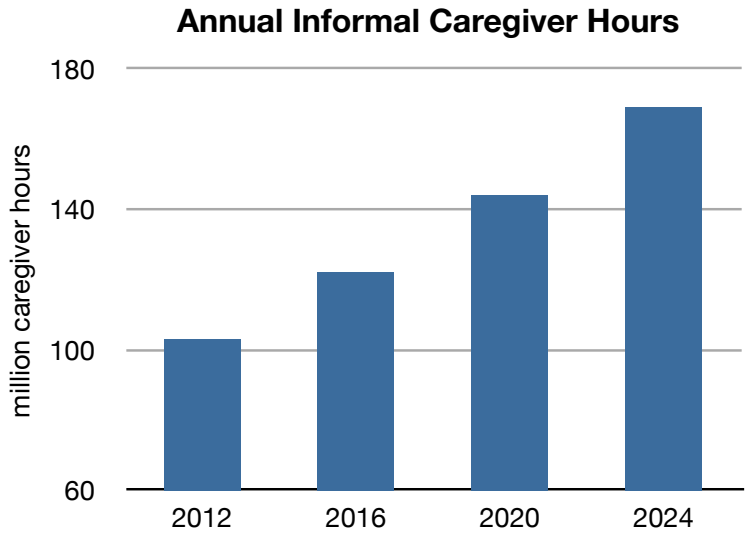
Family caregivers experience physical, psychological, and emotional strain as well as financial hardship and occupational insecurity.[22] Moreover, one quarter of informal caregivers are living with two or more chronic health problems.[23] Individuals providing informal care for someone with dementia are at high risk for depression and stress that can aggravate their own existing conditions thereby magnifying the strain that dementia places on scarce health care resources.

In a recent national survey of *Alzheimer's disease caregivers* aged 44 to 64 years old (non-spouse)[24]

- 35% reported declines in general health; this rate increased to 60% among live-in caregivers
- 71% reported disruptions to employment, and 14% of those surveyed were forced to leave work or retire early

This year, Ontarians caring for family members and friends with dementia will contribute an estimated 100 million unpaid caregiving hours. This number is expected to grow steadily to more than 120 million hours by 2020.[25]

Figure 6.



[22] Miller et al. International Journal of Geriatric Psychiatry, 2012, 27: 382-393.

[23] Health Council of Canada, op. cit.

[24] Black et al. International Journal of Geriatric Psychiatry, 2010, 25: 807-813

[25] Alzheimer Society of Ontario, 2009, Rising Tide: The Impact of Dementia in Ontario, 2008-2038.

Conclusion

The Alzheimer Society of Ontario has presented this evidence brief with data that draws upon authoritative studies recently completed in Ontario and Canada, along with other scientific literature. The document is also intended to demonstrate the epidemiological evidence of the growth of dementia and its projected impact on Ontario's health system at a regional level.

The Institute for Clinical Evaluative Sciences (pages 47, 58, 60, 62 and 64 of report accessed at http://www.ices.on.ca/file/ICES_AgingReport_2011.pdf), the Canadian Institute for Health Information (pages 8 and 9 of report accessed at https://secure.cihi.ca/free_products/ALC_AIB_FINAL.pdf), the House of Commons Standing Committee on Health (Section 4 'Increased Focus on Mental Health' of report accessed at http://www.parl.gc.ca/content/hoc/Committee/411/HESA/Reports/RP5600468/hesarp08/hesarp08-e.pdf) and the National Wait Times Alliance (pages 10-12 of report accessed at http://www.waittimealliance.ca/media/2012reportcard/WTA2012-reportcard_e.pdf) have all pointed to dementia as the main diagnosis driving up ALC rates.

Unfortunately there is a major disconnect between this critical finding and health care policy and practice at the provincial and LHIN levels. Despite the undeniable fact that dementia is the main diagnosis driving up ALC rates, dementia care is not central to either provincial or LHIN level planning. Unless improved dementia care becomes a central part of provincial and LHIN-level planning, policy, investment and action, the ALC crisis will not be resolved, but rather will worsen as will "acute care hospital bed gridlock."

As part of the mandate of the Integrated Health Service Plans (IHSP) is to consider major trends and respond at a local level, we are urging the local LHINs to adopt an integrated care strategy that encompasses major chronic conditions and acknowledges the confounding, cumulative impact of dementia by making improved dementia care a central component of the next IHSP.

Acknowledgements

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Appendix

Dementia projections for Ontario LHINs[26]

LHIN Region	2012	2016	2020	% Increase 2012-2016	% Increase 2012-2020
Erie St. Clair	10,640	11,960	13,260	12%	25%
South West	16,020	18,050	20,170	13%	26%
Waterloo Wellington	10,110	11,780	13,570	17%	34%
Hamilton Niagara Haldimand Brant	25,090	28,300	31,460	13%	25%
Central West	7,950	9,880	12,060	24%	52%
Mississauga Halton	13,340	16,210	19,350	22%	45%
Toronto Central	17,550	19,010	20,100	8%	15%
Central	23,320	28,220	33,330	21%	43%
Central East	24,590	28,590	32,740	16%	33%
South East	9,000	10,290	11,600	14%	29%
Champlain	18,360	21,000	23,950	14%	30%
North Simcoe Muskoka	7,570	8,880	10,340	17%	37%
North East	9,710	11,010	12,320	13%	27%
North West	3,850	4,220	4,600	10%	19%

[26] Dementia prevalence was calculated using 2006 Census-based Ministry of Finance Population Estimates (2001-2010) & Projections (2011-2036) for Local Health Integration Networks (unpublished, updated May 2011) and prevalence rates from the Alzheimer Society of Ontario, "Projected Prevalence of Dementia: Ontario's Local Health Integration Networks," April 2007 (based on the Canadian Study of Health and Aging, 1994).