

Building a Dementia Care System That Works

The need for a minimum service standard for dementia care across all Ontario Health Teams

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Next year, the number of Ontarians living with dementia will pass a quarter of a million.¹ The actual impact of dementia is much greater; beyond the person living with dementia, the lives of care partners, family members, friends, and health care workers are also affected.

In addition to the emotional and financial strain for Ontario families, dementia represents a pressing crisis for our health-care system. Without proper support, families are at risk of reaching a crisis point, where care partners can no longer provide care. These crisis situations lead to avoidable admissions to hospital, a contributing factor to hallway health care. People living with dementia account for nearly a third of alternate level of care (ALC) beds in Canada,² further overwhelming our already crowded hospitals.

The current system is not sustainable. As the first report from the Premier's Council on Improving Healthcare and Ending Hallway Medicine notes, dementia will cost Ontario nearly \$325 billion between 2008 and 2038.³ For such a staggering cost, we can do better.

Community supports will play a major role in Ontario's efforts to end hallway health care. Programs such as counselling, care partner education, and support groups help delay admission to long-term care, and lower the risk of preventable hospital admissions. Community support services also represent a distinct cost savings to our health-care system: an ALC bed costs an average of \$730 per day, compared to the Alzheimer Society's average client cost of \$3 per day.⁴ Placing greater emphasis on community supports will help address hallway health care, delivering cost efficiencies for our health-care system and better outcomes for those who rely on it.

The provincial government's focus on breaking down barriers to better patient care is promising. Ontario Health Teams (OHTs) have the potential to build a more patient-centred health-care system, and reduce the burden on patients, care partners, and families.

¹ Hopkins, R. Dementia Projections for the Counties, Regional Municipalities, and Census Divisions of Ontario. PCCC Mental Health Services. 2010.

² McCloskey, R. Alternate Level of Care Patients in Hospitals: What Does Dementia Have To Do With This? Canadian Geriatrics Journal, 2014, 17(3) pp. 88-94.

³ Premier's Council on Improving Healthcare and Ending Hallway Medicine. Hallway Health Care: A System Under Strain. 2019, p. 16.

⁴ Alzheimer Society of Ontario. Supporting Ontario Families Living With Dementia. 2019, p. 5. Average cost of providing counselling, care partner education, and support group services is \$1,100 per year, or \$3.01 per day.

The OHT model also presents an opportunity for community-level collaboration and province-wide leadership on the critical issues facing our health-care system, including dementia. Dementia and other complex conditions require a specific, targeted approach, with a unique model of care.

To fully realize the potential of OHTs, the Alzheimer Society of Ontario recommends that the following minimum services and standards for dementia care be provided by every Ontario Health Team, at maturity (see Appendix):

- **Dementia-specific system navigation.**
- **Counselling, education, and support for people living with dementia and care partners.**
- **Respite for care partners, inclusive of Adult Day Programs.**
- **Therapeutic recreation services.**
- **Meaningful engagement of people living with dementia and care partners, including the right to participate as fully as possible in decisions affecting care, from diagnosis to end-of-life, in keeping with the *Canadian Charter of Rights for People with Dementia*.⁵**

In addition to the above minimum standards, the Alzheimer Society of Ontario expresses its support for recommendations of the Provincial Geriatrics Leadership Office, contained in their May 7, 2019 position statement.⁶

By incorporating each of these services and standards, Ontario Health Teams will have a solid foundation of support for families affected by dementia in their service area. Each component of the minimum service standard represents a vital lifeline to Ontarians living with dementia and care partners, and each helps to prevent unnecessary hospital visits. A strong emphasis on community supports will help alleviate the urgent problem of hallway health care, driving down costs and improving care.

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⁵ www.alzheimer.ca/charter

⁶ <https://www.rgps.on.ca/resources/position-statement-on-the-need-for-expert-clinical-care-for-older-people-living-with-complex-health-conditions/>

Appendix: Rationale

Dementia-specific system navigation:

The health care system can be confusing to navigate for anyone, much more so for a person living with dementia or a care partner. Referral to a specially trained, dementia-focused care navigator through the provincially-funded First Link[®] program has been shown to connect people living with dementia with vital supports 11 months sooner than when families are left to navigate the system on their own. Dementia-specific system navigation also results in greater knowledge of Alzheimer's disease and other dementias, for both the person living with dementia and their care partner. Crucially, dementia-specific care navigation has been shown to decrease caregiver stress, providing a vital lifeline to overworked care partners.⁷ Reduction in stress benefits the person living with dementia as well, with three-quarters of those given access to dementia-specific system navigation reporting they feel less overwhelmed as a result of the services and support they received.⁸

Counselling, education, and support for people living with dementia and care partners:

The combination of these services has been shown to delay long-term care placement by over 11 months, at a cost savings of over \$50,000 to Ontario families and our health-care system.⁹ By contrast, a combination of counselling, care partner education, and support groups can be delivered, on average, for \$1,100 per year—less than the cost of two days in a hospital ALC bed.

Respite for care partners, inclusive of Adult Day Programs:

Forty-five per cent of care partners to someone living with dementia report distress—nearly double the rate among care partners as a whole. The risk of burnout and distress rises in proportion to the number of hours a care partner spends giving care every week: those who devote over 20 hours a week are three times as likely, and those providing between 11 and 20 hours a week are twice as likely to report feeling distress, compared to those providing under 10 hours of care per week.¹⁰ In the words of a care partner from Sault Ste. Marie, “a caregiver must be given care, or you will end up with two patients.”

Aside from emotional distress, there is an economic cost to leaving care partners under-supported. Caregiving responsibilities often force care partners—predominantly women—to reduce work hours, not seek a promotion, or withdraw from the labour force altogether. Across Canada, care partners devoted 444 million hours of unpaid care in 2011, representing \$11 billion in lost income. Many are unable to cope with the financial burden, and one in five care partners report receiving financial assistance, often from family and friends.¹¹

⁷ McAiney, Carrie A et al. ‘Throwing a Lifeline’: the role of First Link[™] in enhancing support for individuals with dementia and their caregivers. *Neurodegenerative Disease Management*, 2012, 2(6), pp. 623-638.

⁸ Centre for Community Based Research. *First Link Care Navigation Program, Evaluation Report Year 2*. 2019.

⁹ Alzheimer Society of Ontario, p. 5.

¹⁰ Canadian Institute for Health Information. *Dementia in Canada*, 2018.

¹¹ Alzheimer Society of Canada. *The time is now: Fully funding Canada's first national dementia strategy*. 2019, p. 4.

In addition, individuals diagnosed with young onset dementia—referring to a diagnosis before age 65, or about three per cent of Canadians living with dementia¹²—are often still working at the time of diagnosis, and carry financial commitments such as mortgages and loans. These individuals require a unique care plan, including age-appropriate day programming separate from the services available to senior citizens living with dementia. This need is not being met,¹³ representing a gap in our health-care system that can and should be addressed by Ontario Health Teams.

Therapeutic recreation services:

People living with dementia are often excluded from mainstream recreational programs, as a result of cognitive deficits or potential need for support. This contributes to social isolation, decreased activity, and compromised health and wellbeing, for both the person living with dementia and their care partner. With appropriate supports and opportunities, Ontarians living with dementia and their care partners can enjoy greater quality of life.

What's good for the heart is good for the brain; this includes regular activity, both mental and physical. Among older adults with Alzheimer's disease, regular physical activity can improve mobility, balance, day-to-day life skills, and reduce depression.¹⁴ Programs such as Minds in Motion® combine mental stimulation, social interaction, and age-appropriate exercise. These activities have lasting benefits, including improved cognitive performance for up to three days following the recreational activity. Regular therapeutic recreation has been shown to improve endurance and strength by 20 per cent and 15 per cent, respectively. Crucially, the services have a lasting impact: four out of five participants reported continuing with regular physical activity and social interaction following the end of the therapeutic program.¹⁵ Participants speak highly of the program's overall impact on quality of life.

Meaningful engagement of people living with dementia and care partners, including the right to participate as fully as possible in decisions affecting care, from diagnosis to end-of-life, in keeping with the Canadian Charter of Rights for People with Dementia:

The Alzheimer Society of Canada Advisory Group, composed of people living with dementia from all walks of life across the country, developed the *Canadian Charter of Rights for People with Dementia*. Among the rights deemed most important was: "To get the information and support I need to participate as fully as possible in decisions that affect me, including care decisions from the point of diagnosis to palliative and end-of-life care."

As Ontario moves towards a more patient-centred health-care system, we must listen to the voices of patients and care partners. In this instance, those affected by dementia have identified meaningful inclusion in their care plan as being a crucial right.

¹² Canadian Institute for Health Information.

¹³ Alzheimer Society of Durham Region. Young Onset Adult Day Program Evaluation Report (2018-2019). 2019.

¹⁴ Ontario Brain Institute. The Role of Physical Activity in the Prevention and Management of Alzheimer's Disease—Implications for Ontario. 2013. The study only examined Alzheimer's disease, not other forms of dementia.

¹⁵ Alzheimer Society of Ontario. What is Minds in Motion? 2019.