

Help for Today, Hope for Tomorrow

PRE-BUDGET SUBMISSION 2024



**In Ontario, dementia is
hallway health care.**

**Dementia is
long-term care.**

**We can, and must,
do better.**

Summary of Recommendations

1. Renew Ontario's Dementia Strategy.
2. Create a central body, with funding control, to provide strategic direction for dementia care across Ontario.
3. Provide \$3.4 million in additional, ongoing funding to the First Link® program, providing direct support to 6,980 more Ontarians living with dementia and their care partners.
4. Prepare for the imminent arrival in Ontario of disease-modifying treatments for Alzheimer's disease by:
 - a. Funding \$150 million per year, over 10 years, to ensure that all Ontarians living with or at risk of dementia have access to team-based primary and specialist care.
 - b. Providing coverage through the Ontario Health Insurance Plan (OHIP) for positron emission topography (PET) scans and cerebrospinal fluid (CSF) analysis and corresponding lumbar punctures for the purpose of diagnosing mild cognitive impairment and Alzheimer's disease, and make preparations to fully utilize expected blood-base biomarker technology.
 - c. Operating existing clinical MRI machines at full capacity, with associated investments in required staffing.

ABOUT THE ALZHEIMER SOCIETY

The Alzheimer Society is a federation of 26 frontline community support service providers, operating in every community across Ontario. We supported over 70,000 clients last year, including both care partners and people living with dementia. We provide education and training to physicians and other health care professionals, as well as to the general public, and work to reduce the stigma that is far too often associated with dementia. As a health service provider, we offer system navigation, care partner respite, adult day programs, therapeutic recreation, and so much more at little or, for nearly all of our programs, no cost to families. With hundreds of staff and thousands of volunteers we seek to alleviate the personal and social consequences of Alzheimer's disease and other types of dementia, and to promote research into a cure. Learn more and find an Alzheimer Society near you: <https://alzheimer.ca/on/en/about-us/find-your-local-alzheimer-society>

Treatments are coming. Ontario isn't ready.

Two comparable jurisdictions, the United States and Japan, now have an approved, effective disease-modifying treatment for Alzheimer's disease. Canada isn't far behind—and we are not prepared.

At the 2013 G8 Health Ministers meeting in London, world leaders (Canada included) set an ambitious target: identify a disease-modifying treatment for dementia by 2025. This goal has been met: for the first time ever, there are treatment options available to alter the clinical progression of Alzheimer's disease.

The United States became the first country in the world to approve a treatment, with Japan following in 2023. A second disease-modifying treatment published positive phase three clinical trial results in the same year, with the manufacturer pledging to submit for regulatory approval worldwide in the coming years.

Health Canada is reviewing what will likely become Canada's first-ever approved, disease-modifying treatment for Alzheimer's disease. This anticipated approval will be the first of several to come.

Within the mandate of the current Legislature, Canada will likely have an approved disease-modifying treatment for Alzheimer's disease. Within the current decade, we will likely have multiple such treatments.

These scientific breakthroughs promise to revolutionize dementia care—and Ontario is at risk of lagging behind.



Minds in Motion® Exercise Program, Alzheimer Society Peterborough, Kawartha Lakes, Northumberland and Haliburton

All treatment options likely to be approved in Canada in the near future must be administered early. That means early detection and diagnosis—two things Ontario does not do well, with the overwhelming majority of people living with dementia in this province receiving a probable, not confirmed diagnosis, and even that comes late in the disease progression.

The scale of this challenge is difficult to overstate: in the first year of treatment availability, over 90% of Ontarians who seek one will be unable to receive a diagnosis. By the end of that first year, a waitlist of nearly 150,000 Ontarians seeking an eligibility assessment will have formed—the highest in Canada.

Bottlenecks also exist following diagnosis. The first disease-modifying treatments to arrive in Canada will be administered intravenously, requiring twice-monthly appointments in a health care setting. To monitor safety and efficacy, regular MRI scans will also be required. In the first year alone, Ontario will need to provide 96,000 infusion appointments and 16,000 additional MRI scans. There is no realistic prospect of meeting this demand with current staffing and infrastructure capacity.

Due to these bottlenecks and narrow eligibility criteria, a majority of Ontarians living with dementia will be ineligible to receive emerging treatment options, at least in the years following their approval. This includes the roughly 35% of Ontarians who have a form of dementia not caused by Alzheimer's disease.

These Ontarians must not be forgotten in the excitement surrounding disease-modifying treatments. Efficient, person-centred home and community care options will remain a vital component of Ontario's dementia care system indefinitely.

Budget 2024 will in all likelihood be the last major government fiscal policy document developed before Canada has a disease-modifying treatment for Alzheimer's disease. This is the last chance Ontario has to be proactive, not reactive; the final opportunity to avert a looming crisis in care.

The four recommendations contained in this submission would, if implemented, make a measurable positive impact in the lives of Ontarians currently living with dementia, and those who will be diagnosed in the years to come. They are modest and targeted, designed to have an immediate effect on systemic stresses within our health and long-term care systems.

We, the Alzheimer Society of Ontario and the clients we have the honour to serve, submit these recommendations with respectful urgency.

We have no time to lose.

Policy Recommendations

1. Renew Ontario's Dementia Strategy.
2. Create a central body, with funding control, to provide strategic direction for dementia care across Ontario.

Dementia is a \$30 billion disease annually in Ontario, and by 2043 we will spend over \$27 billion on long-term care and ALC costs associated with dementia—much of which is avoidable. One-in-three voters in Ontario have a close family connection to dementia, and over 175,000 Ontarians provide nearly five million hours of unpaid care to someone living with dementia each and every week.

Despite the staggering scale of dementia in Ontario, care planning and provision is disjointed, ineffective, and disorganized. The experiences of Ontarians trying to access dementia care vary widely based on their location, provider, and just pure chance. This would never be an acceptable status quo for any other disease.



Minds in Motion® Program, Alzheimer Society Toronto

Part of this inefficiency is due to the lack of a coordinating, central body overseeing dementia care in Ontario. This responsibility is split between multiple Ministries, including Health, Long-Term Care, and Seniors and Accessibility, and multiple agencies, including Ontario Health, its regional offices, and Ontario Health Teams. **When dementia care is everyone's responsibility, it is no one's.**

The Government of Ontario can take two concrete steps immediately to better coordinate dementia care, leading to improved outcomes for both patients and providers. The first is to renew Ontario's moribund dementia strategy.

Ontario's most recent attempt at a dementia strategy ended with the 2018 provincial election. Since then, what government news releases call a dementia strategy is merely a loosely related set of investments: there is no overarching vision, no central planning, no goals by which the so-called strategy can be measured.

When dementia care is everyone's responsibility, it is no one's.

Properly developed and resourced dementia strategies have been highlighted by the World Health Organization as a powerful tool for establishing dementia as a public health priority. Developing a robust, renewed Ontario Dementia Strategy would bring us into line with this international standard, and establish Ontario as a leader in dementia care among Canadian provinces and territories.

In order to effectively administer a renewed Ontario Dementia Strategy, we call on the provincial government to create a central coordinating body—with funding control—for dementia care in Ontario. This could take the form of a quasi-independent body within Ontario Health, such as Cancer Care Ontario, or a dedicated department within the Ministry of Health. Whatever form this coordinating body takes, best practices both domestically and internationally suggest two non-negotiables: it must have funding control, and it must have meaningful participation from funding Ministries.

3. Provide \$3.4 million in additional, ongoing funding to the First Link® program, providing direct support to 6,980 more Ontarians living with dementia and their care partners.

People living with dementia in Ontario are at higher risk of hospitalization, spend longer in hospital, are more likely to suffer hospital-induced harm, and are more often subjected to physical and chemical restraints in long-term care than older adults without dementia. These traumatic events are often traced back to a single crisis. Cases like this play out every day across Ontario: an emotionally-drained care partner is pushed passed her breaking point one night leading to a visit to the emergency department for her and her husband living with dementia. This leads to a 16-hour wait for care during which responsive behaviours present, which in turn lead to a three-week hospital stay, during which time the husband's cognitive condition declines significantly and he is added to the crisis wait list for a long-term care bed. This then results in the husband getting a bed after a month-long alternate level of care (ALC) hospital stay.

Avoiding these crisis situations is crucial for patient outcomes and health system value: a person living with dementia, once hospitalized, is six times more likely to be admitted to long-term care than someone at home. Long-term care admission for people living with dementia is a one-way street, the start of which is often an entirely avoidable crisis.

Health card data shows that for every three people connected to First Link®, one emergency department visit is avoided.



First Link® is proven to avoid these crises. Health card data shows that for every three people connected to First Link®, one emergency department visit is avoided. Interviews with care partners helped by First Link® reveal they are more confident in providing care, and as a result were able to keep their supported person at home longer.

Despite these demonstrable successes (revealed through government-funded evaluations), funding for First Link® has remained frozen at 2018 levels. The Ministry of Health has funded an impactful health care program, paid to collect data to demonstrate its impact—and then refused, for five years, to act on this evaluation data and scale up a successful service.

We are calling for \$3.4 million in additional base funding to expand the successful First Link® program, enabling us to serve an additional 6,980 clients, provide more intensive support to existing clients, and avoid 1,012 emergency department visits, 405 admissions, 6,882 days spent in hospital, and \$4.89 million in unnecessary costs—a net return of \$1.5 million on this funding ask.

4. Prepare for the imminent arrival in Ontario of disease-modifying treatments for Alzheimer's disease by:

- a. Funding \$150 million per year, over 10 years, to ensure that all Ontarians living with or at risk of dementia have access to team-based primary and specialist care.
- b. Providing coverage through the Ontario Health Insurance Plan (OHIP) for positron emission topography (PET) scans and cerebrospinal fluid (CSF) analysis and corresponding lumbar punctures for the purpose of diagnosing mild cognitive impairment and Alzheimer's disease, and make preparations to fully utilize expected blood-base biomarker technology.
- c. Operating existing clinical MRI machines at full capacity, with associated investments in required staffing.

Disease-modifying treatments for Alzheimer's disease are coming. Ontario is not ready—and this lack of foresight will lead to unnecessary suffering and avoidable costs.

Health Canada received its first-ever request to approve a disease-modifying treatment for Alzheimer's disease in May of 2023. This treatment, lecanemab, has already been approved by regulators in the United States and Japan, and Health Canada's approval is widely expected in the spring of 2024—meaning it will likely be available to patients in Ontario sometime in 2025, within the mandate of the current provincial government. The 2024 provincial budget is the last chance Ontario has to meaningfully prepare for, rather than react to, the arrival of disease-modifying treatments for Alzheimer's disease.

With current capacity, just 2% of Ontarians will have access to the health care supports necessary to access soon-to-be-approved treatment options. In the first year of availability alone a waitlist of 148,000 Ontarians will form in need of eligibility assessments. Similarly high wait lists will emerge for diagnosis and treatment.

At no step of the patient journey is Ontario prepared to administer disease-modifying treatments for Alzheimer's disease—and Ontarians will be denied access as a result.

Other provinces are in a similar situation: some better, some worse, but none adequately prepared for what is coming. This is an opportunity for Ontario to be a leader among its Confederation peers.

Three main bottlenecks will emerge when new treatments are approved: early detection and diagnosis, infusion capacity, and MRI capacity. Only by solving each of these barriers can Ontario benefit from the impending reality of a world with disease-modifying treatments for Alzheimer's disease.

The above three recommendations, developed by the Ontario Dementia Care Alliance, should be seen as the bare minimum to prevent Ontarians being last in line to receive life-altering treatment options.

Targeted Solutions to Improve Dementia Care

There are over 300,000 Ontarians living with dementia today, a number that will grow by 100,000 before the end of the decade. We have no time to lose.

The imminent arrival of disease-modifying treatments for Alzheimer's disease is a generational opportunity—and challenge—to transform dementia care. The status quo is not working: overcrowded hospitals filled with Ontarians living with dementia who have nowhere else to go, long-term care homes operating past their breaking points to care for residents living with dementia who do not need to be there, and care partners unfairly expected to shoulder the unmanageable burden placed on them by a crumbling care system.

Treatments will not single-handedly fix this—but they do offer an additional avenue to keeping Ontarians living with dementia out of hospital and long-term care for as long as possible.

Budget 2024 is a defining fork in the road for how Ontario will fare when disease-modifying treatments arrive. Continued lack of action, investment, and urgency will deprive thousands of Ontarians who will soon be diagnosed with Alzheimer's disease of their one and only chance to benefit from emerging treatment options—treatments that must be administered early.

At the same time we cannot leave those who will not benefit from disease-modifying treatments behind. Successful home and community care programs, like First Link®, should be expanded to keep Ontarians living with dementia where they want to be: at home.

We submit these recommendations with sincere hope that this will be the year Ontario chooses to be a leader in dementia care. The Alzheimer Society is a ready and willing partner in working towards that goal.



Finding Your Way® Education Session for First Responders

**Together, we can
build a dementia care
system that works.**



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