



Action for Dementia

2025 Pre-Budget Submission

Executive Summary

Dementia care in Ontario is at a critical juncture, with over 316,000 Ontarians currently living with dementia – a number expected to triple by 2050.¹ Dementia presents significant challenges to individuals, families, care partners, and the healthcare system, costing the province over \$30 billion annually.² People living with dementia are disproportionately impacted by preventable crises, such as more frequent and extended hospital stays, hospital induced harm, and unnecessary long-term care admissions due to insufficient community supports. These admissions often become a “one-way street”, reducing opportunities to support individuals in their homes and communities, leading to decreased quality of life and increasing strain on healthcare resources.

The Ontario government has an opportunity to address these challenges through proactive planning and targeted investments, transforming dementia care and positioning the province as a leader in innovative, patient-centered approaches. Alzheimer Society of Ontario programs that support hospital diversion, training, day programs, transitional supports, diagnosis, and system navigation have already demonstrated significant impacts in preventing crises, keeping people living with dementia safely in their communities, and generating cost savings for the system. Passing and implementing legislation to create a dementia framework and establishing a central coordinating body provides the vision and leadership needed to improve care outcomes, enhance system efficiency, and reduce unnecessary hospital and long-term care admissions.

The Alzheimer Society of Ontario congratulates the Ontario government on its emphasis to improve dementia care in the province. Passage of the *Improving Dementia Care in Ontario Act, 2024* represents a significant step in redefining the dementia care system and addressing health workforce training. Similarly, the introduction of the *Support for Seniors and Caregivers Act, 2024* entrenches a commitment to support seniors and care partners across all care settings.

While these legislative milestones are commendable, more work is needed. By implementing the recommendations outlined in this submission, the Ontario government can establish a sustainable dementia care framework – one that not only addresses current system gaps but also prepares the system for the future of dementia and disease-modifying therapies. The following recommendations outline essential policy enablers and shovel-ready investments that can transform dementia care across the province:



¹ Alzheimer Society of Canada (2022). *Navigating the Path Forward for Dementia in Canada: The Landmark Study Report #1*. <https://alzheimer.ca/en/research/reports-dementia/navigating-path-forward-landmark-report-1>.

² Jun, Hankyung; Zehao Shi; Soeren Mattke (2022). *Projected Savings to Ontario's Provincial Budget from Reduced Long-Term Care Home Utilization Due to a Disease-Modifying Alzheimer's Treatment*. *Canadian Health Policy*, SEP 2022. ISSN 2562-9492, <https://doi.org/10.54194/VCID2992>

Shovel-ready Programs for Dementia Investment in Ontario

1. **Hospital and long-term care diversion**
Invest \$16 M beginning in 2025/26 to expand the DREAM Program to 40-50 hospitals to divert hospital admissions for people living with dementia.
2. **Dementia competency training in long-term care for providers**
Invest \$2 M beginning in 2025/26 in U-First!® to train 3000 new long-term care providers; develop and deliver U-First!® for Leaders; and develop and deliver U-First!® refresher course.
3. **Activation and respite for early-stage dementia in diverse communities**
Invest \$2.2 M beginning in 2025/26 in the Social to add 9800 new day program spots for people living with early dementia in diverse communities.
4. **Transitional support to long-term care**
Invest \$5.5 M beginning in 2025/26 in the Transition to Long-term Care Program to support 100 long-term care homes in the province.
5. **Detection and diagnosis of dementia**
Invest \$3.1M beginning in 2025/26 in the Dementia Registry and Cognitive Assessment Program to support early detection and diagnosis of dementia in 8 local Alzheimer Societies.
6. **System navigation and support**
Convert the 2025/26 \$3.45 M enhancement of the First Link® Care Navigation Program into base funding to sustain its delivery and support 7000 new clients per year.

Policy Enablers

- A. Implement the *Improving Dementia Care in Ontario Act* to establish a provincial dementia framework that improves access to dementia care.
- B. Mandate the creation of a coordinating body for dementia care, supported by legislative authority and with funding control, to oversee and direct dementia care across the continuum of care in Ontario.



About the Alzheimer Society

The Alzheimer Society of Ontario is a federation of 26 frontline community support service providers, operating in every community across Ontario. We supported over 84,000 clients last year, including care partners and people living with dementia. We provide education and training to physicians and other health care professionals, as well as to the public, and work to reduce the stigma that is often associated with dementia.

As a health service provider, we offer health and social care programs to our clients, including:

- Adult day programs;
- Care partner respite;
- Cognitive testing and functional assessments;
- Counselling;
- Hospital diversion;
- System navigation;
- Therapeutic recreation; and
- Transitional supports.

Along with hundreds of volunteers, the Alzheimer Society of Ontario seeks 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 at:

alzheimer.ca/on/en/about-us/find-your-local-alzheimer-society

Shovel-ready Programs for Dementia Investment in Ontario

1. Hospital and Long-term Care Diversion

In Ontario, people living with dementia and their care partners often rely on emergency departments as a last resort for care, as well as a transition point to long-term care due to gaps in community supports and respite care. This exacerbates challenges in hospitals, including overcrowded emergency departments and prolonged waiting times. Older adults with dementia have higher rates of emergency visits compared to their peers, and they are also more likely to return for repeated visits within one year.⁵ Specifically, around 66% of older adults with dementia who visited an emergency department returned at least once within the following year.⁶ Many of these visits are preventable with proactive care in the community.

Emergency department wait times in Ontario highlight the strain on the healthcare system, with average wait times for admitted patients exceeding 20 hours in many hospitals.⁷ For those with dementia, emergency rooms are particularly stressful environments, contributing to increased agitation and confusion, further complicating care. By reducing hospital dependency for people living with dementia, programs like the Alzheimer Society of Ontario's Dementia Resource, Education, Advocacy, and Mentorship (DREAM) address the underlying systemic challenges, freeing up resources and improving outcomes for both patients and care partners.

The DREAM Program began in Brantford and has since expanded to 18 hospitals across the Ontario Health West region. DREAM embeds local Alzheimer Society staff in hospital emergency departments, tasked with diverting non-acute people living with dementia away from admission. Diverted patients are offered in-home respite care based on their specific needs, greatly reducing the risk of repeat emergency room visits, admissions, and alternate level of care to long-term care designations – improving patient outcomes and saving health care resources. The 15 original sites have cumulatively served over 3,500 persons living with dementia and have seen more than 2,000 of these patients diverted out of hospital and back to the community (average of 55-60% hospital diversion). DREAM supports delaying the expression of need for long-term care by keeping people living with dementia safely in the community. The DREAM Program has already saved the health system over \$27 M from an original \$3.7 M investment. There are more than 20 additional hospitals that have expressed a desire to implement DREAM in their emergency departments if funded, and more are added to our waiting list for expansion every month. Investing in DREAM can significantly enhance the quality and efficiency of dementia care while relieving pressure on the healthcare system overall.

Funding Opportunity:

- Invest in a three-year expansion of DREAM for province-wide coverage to support hospital diversion for people living with dementia, including:
 - \$16 M in funding in 2025/26 to offer DREAM at 40-50 hospitals;
 - \$24 M in 2026-27 to offer DREAM at 80-90 hospitals; and
 - \$36 M in 2027/28 and ongoing for provincial coverage of DREAM in 120+ hospitals.

⁵ Jones A, Maclagan LC, Watt JA, et al. Reasons for repeated emergency department visits among community-dwelling older adults with dementia in Ontario, Canada. *J Am Geriatr Soc.* 2022; 70(6): 1745-1753. doi:[10.1111/jgs.17726](https://doi.org/10.1111/jgs.17726)

⁶ Jones A, Maclagan LC, Watt JA, et al. Reasons for repeated emergency department visits among community-dwelling older adults with dementia in Ontario, Canada. *J Am Geriatr Soc.* 2022; 70(6): 1745-1753. doi:[10.1111/jgs.17726](https://doi.org/10.1111/jgs.17726)

⁷ Health Quality Ontario. (2024). Time spent in emergency departments. <https://www.hqontario.ca/system-performance/time-spent-in-emergency-departments>

2. Dementia Competency Training in Long-term Care for Providers



With a very high proportion of residents living with mild cognitive impairment and dementia, specialized training in dementia is essential for long-term care home staff to effectively do their jobs.

The Alzheimer Society of Ontario offers a suite of programs called U-First!® that provide concrete strategies for supporting the health and social care needs of people living with dementia in long-term care and their care partners. U-First!® provides in-depth training and skills development on responding to behaviour changes and person-centred care that have been proven to increase the capacity of personal support workers other interprofessional care providers in long-term care homes. Courses are offered as full-day in-person, virtual facilitated workshops, or three-week online self-paced modules.

Thousands of health care providers have taken U-First!® and the demand continues to grow for the courses. Evaluation of U-First!® training has demonstrated increased confidence and competence in responding to behavioural changes and improved ability to communicate with PLWD and among the care team, leading to improved quality of care for residents living with dementia. Care partners also report increased well-being for themselves and the person they support. These successes have led to U-First!® expansion to Nova Scotia, Prince Edward Island, New Brunswick, and British Columbia.

Increased government investment in U-First!® will enhance dementia care in Ontario by training thousands of additional long-term care providers, fostering collaborative care practices, and sustaining high-quality, person-centered support for people living with dementia, ultimately reducing strain on the healthcare system.

Funding Opportunity:

- Invest \$2 M in 2025/26 to:
 - Train 3000 additional providers in long-term care through U-First!®;
 - Establish U-First!® communities of practice for the sharing of effective care strategies;
 - Develop and deliver U-First!® for Leaders – a course for administrators and directors of care – including resources and tools to support long-term care staff mentorship and coaching; and
 - Develop and deliver U-First!® Refresher, a skills maintenance course for past U-First!® participants to sustain their dementia care competencies.
- Invest \$1.5 M in 2026/27 and ongoing to train all care providers in long-term care in U-First!® and maintain a high level of care for residents living with dementia.

3. Activation and Respite for Early-Stage Dementia in Diverse Communities

As the number of people living with dementia continues to rise, so does the immense strain on Ontario's unpaid care partners who already provide an estimated five million hours of care weekly—the equivalent of over 128,000 full-time jobs. Many care partners, acting as unpaid nurses and personal support workers, face unsustainable pressure with little attention to their own well-being. Local Alzheimer Societies have stepped in to support over 84,000 individuals annually, with First Link® Care Navigators conducting over 90,000 interventions. However, access to essential services, like day programs, remains inconsistent, leaving many families on lengthy waitlists and in crisis.

The Social is a mobile day program designed to provide three hours of positive and meaningful activities for people living with dementia in the early stages of dementia, which also offers an equal amount of respite time for their care partners. A highlight of this program is its outreach to underserved communities, and the Social serves as a transition to full-day adult day programs as the disease progresses. The Alzheimer Society of Ontario is building a train the trainer model to recruit community members who will build culturally sensitive programming that will be delivered to clients by the members of the communities they live in, without financial barriers, so that all individuals can benefit from the program's support.

Funding Opportunity:

- Invest in a five-year expansion of the Social to provide meaningful day programming to people living with early dementia in diverse communities, including:
 - \$2.2 M in 2025/26 to add 9800 new day program spots;
 - \$2.6 M in 2026/27 to add an additional 14,700 new day program spots;
 - \$3.6 M in 2027/28 to add an additional 24,500 new day program spots;
 - \$4.6 in 2028/29 to add an additional 53,900 new day program spots; and
 - \$5.3 M in 2029/30 and ongoing to add an additional 73,500 day program spots.

4. Transitional Support to Long-term Care

Moving to long-term care is a stressful and traumatic experience for anyone, whether from home or from hospital. For the more than 70% of long-term care residents in Ontario who live with dementia, an abrupt change in environment, routine, and surroundings can be overwhelming – leading to rapid decline in physical and cognitive health. Approximately one-third of newly admitted residents will visit the emergency department within 30 days of moving to long-term care – and residents who have required hospital care once are twice as likely to visit hospital again.

Transitional support to help residents living with dementia in long-term care adjust to their new surroundings is crucial to avoiding unnecessary hospitalizations. The Alzheimer Society of Ontario's Transition to Long-Term Care Program assigns local Alzheimer Society staff to help people living with dementia prepare for a move to long-term care, including activation support for up to three weeks following their move. This program has demonstrated success as hospitalization rates for newly admitted people living with dementia have fallen dramatically in the region. For example, the Alzheimer Society of Sault Ste Marie & Algoma District has supported more than 400 transitions to long-term care. Only one client required transfer to hospital when supported by the Program, due to an undiagnosed urinary tract infection. This is compared to an estimated one-third of new residents who require a hospital visit during their transition period.

Funding Opportunity:

- Invest in a five-year expansion of the Transition to Long-Term Care Program to support all 627 long-term care homes in Ontario, including:
 - o \$5.5 M in 2025/26 to support transitions to 100 long-term care homes;
 - o \$13.3 M in 2026/27 to support transitions to 250 long-term care homes;
 - o \$20 M in 2027/28 to support transitions to 375 long-term care homes;
 - o \$26.2 M in 2028/29 to support transitions to 500 long-term care homes; and
 - o \$32.8 M in 2029/30 and ongoing for provincial coverage of all 627 long-term care homes in Ontario.

5. Detection and Diagnosis of Dementia

For the first time, Canadians have hope for changing the course of Alzheimer's Disease as we await approval from Health Canada for disease-modifying therapies for dementia. Such treatment options, already approved in the United States, Japan, and the European Union among others, give promise to revolutionizing dementia care for future generations.

Early detection and diagnosis are critical to the success of these treatments. However, most Ontarians living with dementia currently receive only a probable diagnosis, often late in their disease progression. Without proactive investment and planning for early detection, diagnosis, and treatment, the province will face growing waitlists and missed opportunities for care. Such a delay will result in significant barriers to accessing treatment once it's available, where over 90% of Ontarians who seek treatment may be ineligible due to late diagnosis and capacity issues.⁸

The Alzheimer Society of Ontario, in partnership with the Ontario Brain Institute, co-developed a Dementia Registry and Cognitive Assessment Program, which captures real-world evidence on Alzheimer's Disease while supporting the rollout of disease-modifying therapies (when approved), creating opportunities for better care alongside testing of new neurotechnology innovations with registry participants. The Alzheimer Society of Ontario and the Ontario Brain Institute are validating a digital cognitive assessment (in partnership with MoCA) that can help identify individuals who require a cognitive assessment, alongside a program where an Alzheimer Society of Ontario staff will conduct cognitive testing and functional assessments for clients referred by their primary care provider. The Program ensures earlier access to cognitive tests while reducing the bottlenecks for diagnostic testing by dementia care specialists.

By funding the Dementia Registry and Cognitive Assessment Program, Ontario can better position itself to provide timely access to new dementia treatments, improve early detection and diagnosis, and alleviate pressure on the healthcare system.

Funding Opportunity:

- Invest in a four-year expansion of the Dementia Registry and Cognitive Assessment Program for province-wide coverage, including:
 - \$3.1 M in 2025/26 for 8 local Alzheimer Societies;
 - \$4.6 M in 2026/27 for 12 local Alzheimer Societies;
 - \$6.7 M in 2027/28 for 20 local Alzheimer Societies; and
 - \$8.7 M in 2028/29 and ongoing for provincial coverage at all 26 local Alzheimer Societies.

6. System Navigation and Support

Crisis situations for people living with dementia can have severe and often avoidable consequences for individuals, families, and the healthcare system. People living with dementia are hospitalized

⁸ Jun, Hankyung; Zehao Shi; Soeren Mattke (2022). Projected Savings to Ontario's Provincial Budget from Reduced Long-Term Care Home Utilization Due to a Disease-Modifying Alzheimer's Treatment. Canadian Health Policy, SEP 2022. ISSN 2562-9492, <https://doi.org/10.54194/VCID2992>

more frequently, spend longer in hospitals, face higher risks of hospital-induced harm, and are six times more likely to enter long-term care – oftentimes prematurely – compared to older adults without dementia. Many of these crises are avoidable with proactive, coordinated support. By addressing these risks early, we can ensure better patient outcomes, improve quality of life, and generate significant value for Ontario’s healthcare system by reducing avoidable strain on hospitals and long-term care facilities.

The Alzheimer Society of Ontario’s First Link® Care Navigation Program helps to connect people living with dementia and their care partners to the information, supports, and services they need as early as possible and throughout the progression of their condition. In 2023/24, First Link® supported over 16,757 clients, including 6,500 new clients, providing more than 30,000 personalized visits. OHIP card data indicate that for every three people connected to First Link®, one emergency department visit is avoided. This not only prevents unnecessary hospitalizations but also delays long-term care admissions as clients can receive care in the community for longer. Interviews with care partners helped by First Link® reveal they are more confident in providing care and they were able to keep their supported person at home longer.

First Link® is an essential part of Ontario’s dementia care landscape, proving that proactive support improves outcomes for families and reduces strain on the healthcare system. Prioritizing its funding is a critical step toward addressing the growing needs of Ontario’s growing population living with dementia.

Funding Opportunity:

- Convert the 2025/26 \$3.45 M enhancement of the First Link® Care Navigation Program into base funding to sustain its delivery and support 7000 new clients per year.

Policy Enablers

- A. Implement the *Improving Dementia Care in Ontario Act* to establish a provincial dementia framework that improves access to dementia care.
- B. Mandate the creation of a coordinating body for dementia care, supported by legislative authority and with funding control, to oversee and direct dementia care across the continuum of care in Ontario.

Despite the significant prevalence of dementia in Ontario, care planning and service delivery remain disjointed, uncoordinated, and inefficient. Without clear objectives and measurable goals for dementia care, families and providers are left navigating a fragmented system with insufficient supports. Access to dementia care is largely determined by factors like geographic location, the availability of providers, and sheer luck – an inequity that would be unacceptable for any other disease.

Globally, the World Health Organization has highlighted dementia strategies as essential tools to drive policy changes that lead to improved health outcomes. These strategies are vital for addressing the challenges and growing needs of a population in which over 316,000 people in Ontario are currently living with dementia, with 100,000 more being diagnosed by 2035.³ Implementing the *Improving Dementia Care in Ontario Act, 2024* would align Ontario with other jurisdictions that have recognized dementia as a public health priority by creating a made-in-Ontario dementia framework that guides the implementation of cost-effective and efficient interventions that support people living with dementia across the continuum of care.

In alignment with recommendations from the 17 expert members of the Ontario Dementia Care Alliance, effectively implementing a plan for dementia requires a central coordinating body responsible for dementia care.⁴ This body must have funding control and be able to facilitate collaboration across relevant ministries for high-quality and evidence-informed dementia care in Ontario. Furthermore, this coordinating body should include meaningful representation from key stakeholders, including care providers and advocacy groups.

With projections showing significant increases in dementia prevalence and associated costs, timely action is imperative.

ABOUT THE ODCA:

The Ontario Dementia Care Alliance is a multi-stakeholder nonpartisan group, including healthcare professionals, community organization experts, education partners, and people with lived experience that facilitate discussions regarding dementia care challenges to increase awareness and to improve quality of care in the province, with a focus on actionable advice and implementable solutions. The ODCA's mission is to create a more dementia-friendly Ontario using expert advice that will educate, advocate, and improve access to quality dementia care across the province. The ODCA is made possible by funding from Eisai Canada, Novo Nordisk Canada, Roche Canada, and administrative support from the Alzheimer Society of Ontario.

³ Alzheimer Society of Canada (2022). Navigating the Path Forward for Dementia in Canada: The Landmark Study Report #1. alzheimer.ca/en/research/reports-dementia/navigating-path-forward-landmark-report-1.

⁴ Ontario Dementia Care Alliance (2024). Promoting Access to Dementia Care in Ontario: Submission to the Ontario Government in Advance of the 2024 Budget. https://alzheimer.ca/on/sites/on/files/documents/Ontario%20Dementia%20Care%20Alliance%20Pre-Budget%20Submission%202024_Final.pdf

Conclusion

Dementia care in Ontario is at a critical juncture - we must meet the high and growing demand with services to address systemic challenges and ensure the province is prepared for the future. Targeted investments in hospital diversion, training, day programs, transitional supports, diagnosis, and system navigation are essential to address the current bottlenecks in the health care system. These investments will also ensure timely access to new disease modifying therapies for dementia when they are approved. These proactive measures will not only alleviate strain on hospitals and long-term care facilities, but they will also position Ontario as a leader in innovative, patient-centred dementia care.

By passing legislation to create a dementia framework and establishing a central coordinating body to oversee dementia care, the government can bring a strategic vision to a fragmented care system to improve the quality of life for people living with dementia and their care partners.

Now is the time to act on dementia care in Ontario. The Alzheimer Society of Ontario stands ready to implement, scale, and spread programs that will meet the needs of the growing population and preserve the health system for future demands.

