

Alzheimer *Society*
ONTARIO

No Time to Lose

PRE-BUDGET SUBMISSION 2023



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

**Dementia is
long-term care.**

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

Summary of Recommendations

POLICY

1. Make a public commitment to renewing Ontario's Dementia Strategy
2. Appoint Ontario's first-ever Dementia Secretariat
3. Develop a clear and consistent dementia care pathway, including planning for future treatments

FUNDING

4. Support more Ontarians living with dementia, their care partners, and families with an investment of **\$3.26** million in First Link® System Navigation
5. Lower hospitalisation rates for newly admitted long-term care residents with **\$21.98** million in funding for transitional activation support
6. Invest **\$7.56** million to divert people living with dementia away from emergency rooms and back where they want to be: at home
7. Expand access to dementia-specific respite services with an initial annual investment of **\$93.5** million
8. Provide an additional layer of community-based options for 2,500 older Ontarians with complex care needs through a **\$57** million investment in assisted living and supportive housing
9. Expand diagnostic capacity through a **\$10** million investment in PET scan centres serving Hamilton, London, Sudbury, and Toronto
10. Create, sustain, and expand interprofessional teams in geriatric clinics at an annual cost of **\$15** million
11. Stabilise MINT Memory Clinics with an immediate one-time investment of **\$11** million
12. Introduce a fully refundable Primary Caregiver Tax Credit at an approximate annual cost of **\$369.6** million
13. Equalise wages between hospital and home and community care workers performing equal work, at an approximate cost of **\$470** million

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 95,000 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.

Right Care, Right Time, Right Place

In Ontario today, dementia care is inefficient and ineffective. This is placing an unmanageable burden on care partners and families—and an unnecessary strain on our health and long-term care systems.

Alternate level of care (ALC) in Ontario's hospitals is a conversation about dementia by another name. It is Ontarians living with dementia who are not getting the care and support they need to stay at home, Ontarians living with dementia who are discriminated against in applying for a bed in long-term care, Ontarians living with dementia who cannot access supportive housing or day programs—and Ontarians living with dementia who have nowhere to go but a hospital when they and their care partners reach a crisis point.

It is little wonder why **50%** of Ontario's ALC days are attributed to an older adult living with dementia. That's around 2,600 hospital beds occupied on any given day in this province by someone living with dementia who does not want or need to be there. This is not their choice: the choice was made for them by a health care system that has systemically underfunded home and community supports for dementia care for decades.

Most ALC patients are waiting for a suitable bed to open up in long-term care, and there too dementia is at the heart of capacity constraints. Two-thirds of long-term care residents in Ontario live with dementia—and again, many of them do not want or need to be there. With proper supports, **8%** of long-term care residents could have stayed living at home—that's around **7,600** beds that could be taken by someone who truly needs one.

Dementia care in Ontario today has an implicitly institutional mindset. The assumption when someone is diagnosed with probable dementia is that, eventually, they will move to long-term care. For some, this is certainly the most appropriate place for them to be—but is by no means the best option for everyone. People living with dementia have the same sense of identity and individuality as anyone else, and the same right to make informed decisions. This right is denied to them today, as they are forced to accept the basic care they need in the only place that can't turn them away: hospitals.

The status quo of institutionalised dementia care isn't working. Innovative solutions to address unsustainable ALC rates are needed—and that means innovative solutions to address dementia care. The Alzheimer Society has 13 recommendations to do better.



Policy Recommendations

Ontario will spend over **\$27 billion by 2043** on long-term care and ALC costs alone to support people living with dementia—much of which is avoidable. Funding is one barrier to quality dementia care, but not the only one: there are meaningful steps the Province can take to improve care with little or no associated cost.

Make a public commitment to renewing Ontario's Dementia Strategy

In early 2022 the Alzheimer Society of Ontario convened a panel of 21 experts in dementia care and asked a simple question: what's wrong with dementia care today? Their detailed feedback led to 77 fully costed recommendations, chief among them being to draft and implement a renewed Ontario Dementia Strategy (ODS). The current ODS was first launched in 2017, and has not lived up to its potential: funding remains frozen at 2018/19 levels, there has never been an evaluation of the Strategy's success, and responsibility for overseeing and implementing the ODS is confused at best. When dementia care is everyone's responsibility, it is no one's: Ontario currently has no clear, overarching vision for improving dementia care, an unacceptable reality for a disease that will triple in prevalence within the next three decades. New funding announced in the 2022 provincial budget was a step in the right direction. Now we urge the Province to go further: use the 2023 budget as an opportunity to renew Ontario's Dementia Strategy. Be the government that finally sets Ontario on course to be a world-leader in dementia care.

When dementia care is everyone's responsibility, it is no one's: Ontario currently has no clear, overarching vision for improving dementia care.

Appoint Ontario's first-ever Dementia Secretariat

Dementia has far-reaching impacts on Ontario's health and long-term care systems, and society as a whole. **There are over 260,000 Ontarians living with dementia today, and nearly a third of all adults in the province have a close relative living with dementia.** While age is the most common risk factor, dementia can affect people into their forties and fifties—with up to 8% of cases across Canada being classified as young onset. As a progressive disease, the care needs of someone living with dementia evolve and can encompass primary care, home and community care, acute care, and long-term care—effectively, one person living with dementia can and often does interact with the entirety of Ontario's health and long-term care systems over the course of their dementia journey. Other, equally complex diseases, such as cancer, have dedicated strategies and steering bodies. Dementia does not, and as a result care is disjointed and reactive rather than proactive. We call on the Government of Ontario to change this by establishing a Dementia Secretariat within Ontario Health, with a mandate to oversee dementia care and make recommendations across the spectrum of government services including health and long-term care.

Develop a clear and consistent dementia care pathway, including planning for future treatments

Two Ontarians who start to exhibit symptoms of Alzheimer's disease or another form of dementia can have remarkably different experiences getting a diagnosis and accessing support. Where they live, who their doctor is (or if they have one), whether or not they live near close family, and many other factors determine whether someone will get the answers and help they need, or be left to figure it out on their own. This would never be an acceptable status quo for any other disease.

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From the first conversation with a primary care provider right through to end of life, Ontarians deserve and have the right to know what supports they can access. Health Quality Ontario has developed thorough best practices for dementia care, but these are rarely used; instead, individual providers do the best they can with the resources they have, while the experiences of two people living with dementia in the same community can vary considerably. We call on the Government of Ontario to give families certainty: develop and monitor adherence to a dementia care pathway, including a stream for Ontarians able to access a disease-modifying treatment that is expected this decade. It is entirely possible that the current government will be the one tasked with rolling out Canada's first-ever treatment for Alzheimer's disease. But today, Ontario is not ready.



Funding Recommendations

Dementia costs Ontario over \$10 billion annually in direct care costs. The question is not whether Ontario should spend on dementia care: it is whether this spending will continue to be reactive and inefficient as it is today, or planned and cost-effective.

Support more Ontarians living with dementia, their care partners, and families with an investment of \$3.26 million in First Link® System Navigation

A diagnosis of dementia is a life-altering event. It doesn't have to be a traumatic one. Early connection to a First Link® Care Navigator has been shown to reduce avoidable visits to the emergency room, delay admission to long-term care, and improve care partner quality of life. First Link® provides a dedicated and consistent point of contact for families affected by dementia, providing education and support to both the person living with dementia and their care partner(s) and guiding the family to available supports and services suited to their care needs (including but not limited to those offered free of charge by the Alzheimer Society). This vital program has been operating at 2018/19 funding levels for four years, resulting in wait times that average seven months across Ontario—far too long for a family in desperate need of help today. An investment of \$3.26 million would enable First Link® Care Navigators to immediately begin supporting up to 5,000 new clients, and provide a higher standard of support to the over 14,000 clients who currently depend on them.

Lower hospitalisation rates for newly admitted long-term care residents with \$21.98 million in funding for transitional activation support

Moving to long-term care is a stressful and traumatic experience, whether from home or from hospital. For the two-thirds of long-term care residents in Ontario who live with dementia, an abrupt change in environment, routine, and surroundings can be overwhelming—and can lead to rapid decline in physical and cognitive condition. This is why **around 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 a new long-term care resident who lives with dementia adjust to their surroundings is crucial to avoiding unnecessary hospitalisations. An ongoing pilot project supporting LTC homes in and around Sault Ste. Marie, Sudbury, and Timmins aims to do just that: by assigning a community staff member to help a person living with dementia prepare for a move to LTC, then providing activation support for up to three weeks following their move, hospitalisation rates for newly admitted residents living with dementia have fallen dramatically—saving hundreds of thousands of dollars in emergency room costs, which have exceeded the cost of the program itself. In Sault Ste. Marie alone, 156 clients have been successfully supported in their transition to LTC over the past two fiscal years, including 58 in 2021/22 without any public funding. Of these, not one has required a hospital visit during the time they were supported by Alzheimer Society staff—a 100% reduction from the 55 visits that would usually be expected. Even assuming a short one-week hospital stay, the program has saved over a quarter of a million dollars—in this one region alone. The time is right to expand this innovative solution province-wide: we urge the Government to include \$21.98 million to fund long-term care transitional supports across all LTC homes in the province.

Invest \$7.56 million to divert people living with dementia away from emergency rooms and back where they want to be: at home

Hospitalisation rates for older adults living with dementia are 65% higher than for those without dementia, and those living with dementia are also more likely to stay longer in emergency departments, experience harm as a result of a visit to hospital, and stay in hospital for twice as long if admitted.

Both the person and the health care system suffer when someone living with dementia spends time in hospital when they could have been supported at home—with proper supports. A pilot program in the Brantford Brant Ontario Health Team found that embedding community support staff in hospital emergency departments can divert over 60% of individuals living with dementia who present in the emergency room when the community staff member is present—saving over \$5.6 million in avoided costs alone, in one hospital network for one year. Closer working relationships between community and hospital staff are vital to keeping Ontarians living with dementia at home, and we call on the Government of Ontario to expand this successful pilot province-wide with an initial investment of \$7.56 million in Budget 2023—an investment that would be cost positive, considering avoided ALC days.

Expand access to dementia-specific respite services with an initial annual investment of \$93.5 million

In 2019 the Premier's Council on Improving Healthcare and Ending Hallway Medicine recommended extended hours for respite care and overnight options to support care partners to Ontarians living with dementia. Since this report, very little has been done to act on this recommendation: care partners are still burnt out, overnight respite options are still limited to a handful of urban areas, and wait lists for daytime programs can stretch to seven months (where wait lists are even offered). When care partners are not supported, you end up with two patients. We urge the Province to act on advice from its own expert Council, and create a dedicated funding stream for dementia-specific respite services with an initial budget of \$93.5 million annually.



"For family caregivers supporting patients with dementia, extended hours for respite or additional access to support overnight would help make it possible to keep their family member at home longer rather than moving them to a long-term care home."

– Second report from the Premier's Council on Improving Healthcare and Ending Hallway Medicine, p. 10

Provide an additional layer of community-based options for 2,500 older Ontarians with complex care needs through a \$57 million investment in assisted living and supportive housing

There is a substantial gap in care options between Adult Day Programs and long-term care. Supportive housing and assisted living options fill this gap, but wait lists can stretch into years—where it is available at all. As a result older Ontarians who would otherwise benefit greatly from assisted living or supportive housing must turn either to Adult Day Programs, where their care needs are too great for the level of support provided, or long-term care, despite their care needs not requiring round-the-clock intensive supports. An investment of \$57 million to expand assisted living and supportive housing options would free up capacity in both Adult Day Programs and long-term care, enabling both settings to support more clients who would most benefit from that level of care.

Expand diagnostic capacity through a \$10 million investment in PET scan centres serving Hamilton, London, Sudbury, and Toronto

Earlier detection and diagnosis of Alzheimer's disease and other forms of dementia has been shown to delay admission to long-term care and improve client outcomes. With Canada's first-ever approved treatment for Alzheimer's disease quite possibly on the way this decade, early detection assumes a critical importance (with pending treatments only suitable when the disease is detected at its earliest stage). PET scans are one of the few reliable methods to obtain a complete diagnosis, with most Ontarians today relying instead on a probable diagnosis based on a cognitive assessment. Despite the vital need for PET scans across oncology, cardiology, and neurology, the Province's scan centres are operating below their capacity. An investment of \$10 million annually would enable scan centres—already a tremendous one-time cost to establish—to perform more tests outside of current operating hours in Hamilton, London, Sudbury, and Toronto, where unmet need is greatest.

Ontario has roughly half the number of dementia diagnosis and treatment specialists that it needs.

Create, sustain, and expand interprofessional teams in geriatric clinics with an annual investment of \$15 million

Ontario has roughly half the number of dementia diagnosis and treatment specialists (geriatricians, geriatric psychiatrists, and neurologists) that it needs. Encouraging the recruitment of more such specialists is a long-term solution, however action is needed to address the six- to nine-month wait period Ontarians face today to see a specialist. Supporting Ontario's limited dementia care specialists is crucial to ensure their time is spent most appropriately. This is achieved by embedding specialists in interprofessional teams, including occupational therapists, physiotherapists, social workers, and nurses. Providing funding to offer these health care professionals permanent positions, as opposed to short-term contracts, will lead to stability and greater consistency in care.

Stabilise MINT Memory Clinics with an immediate one-time investment of \$11 million

Ongoing, proactive care is crucial for avoiding crisis situations that can force a family affected by dementia to turn to hospital. The MINT Memory Clinic model builds an expert care team including and around a person living with dementia (or other conditions that affect memory), complementing the experience of the person's own family doctor. Evaluation of the model conducted in 2019 by the then-Ministry of Health and Long-Term Care found that emergency department and hospitalisation costs were halved for those connected with a MINT Clinic. Despite this success, existing Clinics are struggling to stay open. We call on the Province to enable MINT Clinics to continue supporting clients with an immediate investment of \$11 million.

Introduce a fully refundable Primary Caregiver Tax Credit at an approximate annual cost of \$369.6 million

Unpaid care partners save health care systems across Canada an estimated \$25 billion annually in direct care costs—not including a further \$1.4 billion care partners spend out of their own pocket on expenses related to their caregiving. Care partners sacrifice their own mental, physical, and financial wellbeing to care for someone close to them—a sacrifice that is amplified when the person they support lives with dementia. Care partners to someone living with dementia report higher levels of distress and more time spent providing care than the general care partner population. Care partners assume this burden very much on their own: there are no government-funded financial supports available for care partners in Ontario, with the only indirect support being a joint federal/provincial non-refundable tax credit that only 8% of care partners currently access. This is not enough: the number one need expressed by care partners continues to be financial support. We urge the Province to hear the pleas of unpaid care partners, who give so much to others and our health care system, and implement a fully refundable Primary Caregiver Tax Credit based on a similar program available in Manitoba, at an approximate annual cost of \$369.6 million.

Unpaid care partners save health care systems across Canada an estimated \$25 billion annually.

Equalise wages between hospital and home and community care workers performing equal work, at an approximate cost of \$470 million

Robust home and community supports cost the Province around seven times less than a day in hospital, and half of the cost of a day in long-term care. Aside from being cost effective, home is where Ontarians want to be: 95% wish to stay in their own home as they age. Yet this option is increasingly not available, as home and community care providers struggle to recruit and retain staff to deliver funded hours of care. It is not uncommon for positions to be posted multiple times with no applicants, for the simple reason that qualified staff can earn more in the hospital sector in a near-identical role. As home and community care providers struggle to find staff, clients can't get the support they need and have no other option but to turn to hospital—where they are supported by the same staff, at a much greater cost. Research from 2022 sponsored by the Ontario Community Support Association found that providing higher wages in home and community care can be cost beneficial: more staff means more Ontarians kept at home, driving down costs in hospital and long-term care. We call on the Province to do the right thing, for staff and our health care system: pay frontline staff what they deserve, no matter where they work.

Conclusion

The strains faced by our hospital and long-term care staff and infrastructure today are unsustainable. The status quo isn't working—and the status quo is inefficient dementia care. With nowhere else to turn, Ontarians living with dementia are forced into hospital and long-term care settings when they would rather be at home. This produces worse outcomes for the person, and more strain on the system. We have no time to lose in changing this status quo.

*The strains faced by our hospital and long-term care staff and infrastructure today are **unsustainable**.*

Ontario is a world leader in many fields. Dementia care is an embarrassing exception. We call on the Government of Ontario to use Budget 2023 as an opportunity to fix what lies at the heart of capacity constraints in our hospitals and long-term care homes: inefficient, disjointed care offered to Ontarians living with dementia and their care partners. Families, care partners, people living with dementia, and frontline staff have done more than their part—now, they are looking to Government to do theirs.

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

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Alzheimer Society of Ontario

20 Eglinton Avenue West, 16th Floor,
Toronto, Ontario M4R 1K8

Phone: 416-967-5900

Toll-free: 1-800-879-4226

Fax: 416-967-3826

Email: policy@alzon.ca



Charity registration number: 11878 4842 RR0001