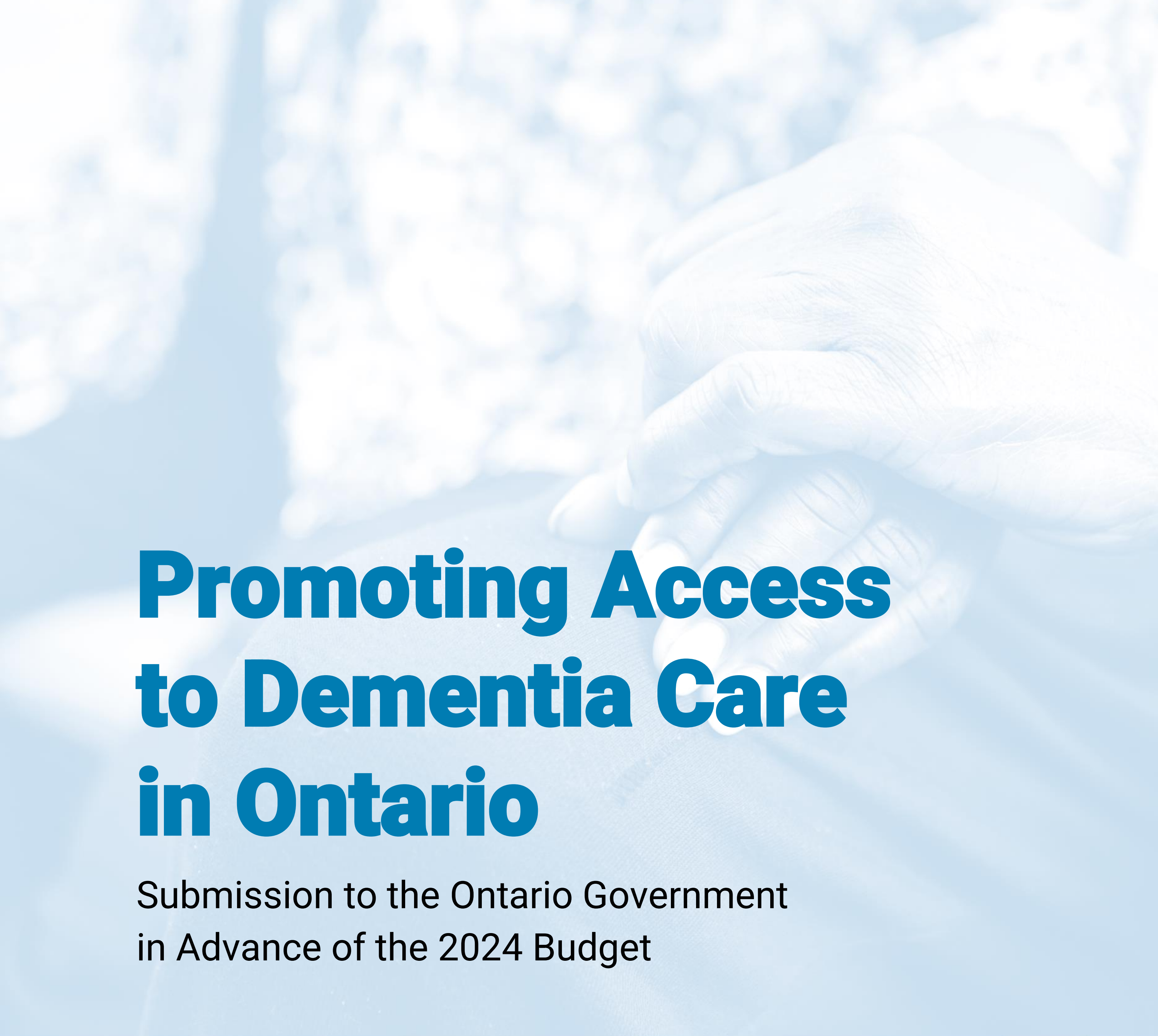

Promoting Access to Dementia Care in Ontario

Submission to the Ontario Government in Advance of the 2024 Budget

Respectfully submitted by the members
of the Ontario Dementia Care Alliance (ODCA)

Ontario
Dementia
Care Alliance

Preamble

Dementia costs Ontario taxpayers over $30 billion annually—a figure that will only continue to rise as our population ages and lives longer. The economic and societal implications of dementia are unavoidable—but they are controllable. It is within the power of the Government of Ontario to choose proactive, not reactive policy—such as the recommendations contained in this document—that minimize the costs of dementia care to the greatest possible extent, providing care in more cost-efficient home and community settings wherever possible and planning to make efficient use of emerging treatments and technologies.

With the forthcoming advent of disease-modifying treatments for Alzheimer's disease, there is an opportunity for Ontario to be both a national and global leader in providing quality, compassionate, efficient dementia care. This is not the status quo in Ontario today. People living with dementia account for the majority of alternate level of care (ALC) beds in Ontario's hospitals, and an even greater majority of its long-term care beds. Over 40,000 Ontarians are on waitlists to access a long-term care bed. Wait times to access both diagnosis and care stretch into years, and many care options are unavailable to Ontarians in rural, remote, and northern regions.

Forthcoming treatment options will radically disrupt and challenge the status quo for diagnosing and supporting people living with Alzheimer's disease—but only if we act now to prepare, for which there is little time remaining. It is likely that Canada will have its first-ever approved treatment for Alzheimer's disease within the next two years—or, put another way, within the mandate of the current provincial government.

These treatments are only effective if administered early. This means catching Alzheimer's disease at its earliest stages: mild cognitive impairment or early Alzheimer's disease. In Ontario today, very few cases are diagnosed at these earlier stages; in fact, most do not receive a confirmed diagnosis at all, but rather a presumptive one. These presumptive diagnoses are insufficient justification for administering treatments. The recommendations, if taken together, will support Ontarians with cognitive concerns to receive an assessment within 12 weeks.

There must be immediate and targeted investments made in dementia-focused teams of professionals in both primary and specialist care settings, and necessary investments made in scans, particularly MRI and PET, as well as fluid biomarkers including cerebrospinal fluid (CSF) analysis and the prerequisite lumbar punctures that are used to diagnose Alzheimer's disease. Ontario also has an opportunity to look to the near future, preparing for the arrival of blood-based biomarker tests that can quickly, inexpensively, and reliably, detect abnormal amyloid and tau presence, both of which will be important in prescribing treatment options.

Ontario must also meet the needs of those living with dementia who are ineligible to receive forthcoming treatments, through fulsome home and community care options. Keeping Ontarians living with dementia at home—where they want to be—both reduces costs to the health care system and improves patient outcomes.

There is currently no centralized responsibility for dementia care in Ontario, undermining this goal. Dementia falls under multiple provincial Ministries, most notably Health, Long-Term Care, Municipal Affairs and Housing, and Seniors and Accessibility. Within these departments there are a myriad of agencies that should, but are not coordinating to deliver efficient, effective dementia care. This stands in sharp contrast to other diseases, including cancer and cardiovascular health, that are coordinated provincially. Dementia is the seventh-leading cause of death in Canada and personally affects nearly one-third of adults in Ontario. In Canada, 83 percent of the care partners for people living with dementia are between 23 and 65 years of age.[i] This demographic, which forms the backbone of Ontario's labour marker, is often unable to fully participate in the workforce and faces job insecurity.

Despite these wide-reaching societal and economic ramifications, the Government of Ontario would struggle to answer the most basic question about dementia care: Who is in charge?

The 17 expert members of the Ontario Dementia Care Alliance (ODCA) have volunteered their combined decades of experience to craft this document, in the hopes that it will start a collaborative dialogue between government and care providers. This document also serves as a warning: dementia will be among the defining public health challenges of the coming decades. The number of Ontarians living with dementia will triple by 2050; no component of our dementia care system, from family doctors to specialists to home and community care to long-term care homes, will be able to meet this demand as they are positioned today.

The ODCA believes that we can, and must do better for Ontarians living with dementia, their care partners, families, and frontline health care workers. Through this submission, the ODCA asks the Government of Ontario to adopt a dementia-focused lens to health system planning, and to incorporate a focus on dementia care and diagnosis in Ontario Health's Aging Care Continuum Strategy and related investments.

Summary of Recommendations

Recommendation 1

a) Develop, implement, and fully fund a comprehensive provincial Dementia Care Strategy, including meaningful targets and outcomes for patient care, care partner supports, and introduction of disease-modifying treatments for Alzheimer's disease.

b) Mandate through legislation the establishment of a coordinating body within a government agency such as Ontario Health dedicated to overseeing dementia care in all settings, implementing a provincial Dementia Care Strategy, and driving meaningful quality improvements for more consistent patient, care partner, and provider experiences. The coordinating body must have an annualized budget and should have a degree of control over the funding of dementia care services, as determined by the provincial government.

Recommendation 2

Fund $150 million per year for 10 years to ensure that all Ontarians living with or at risk for dementia have access to team-based primary and specialist care, such that patients with cognitive concerns are assessed within 12 weeks.

Recommendation 3

a) Operate existing clinical MRI machines at full capacity to improve monitoring capacity that will be required for forthcoming Alzheimer's disease treatments.
b) Provide coverage under 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 through amyloid beta and tau protein detection, and make preparations to fully utilize expected blood-based biomarker technology.

Recommendation 4

a) Support people living with dementia and their care partners with aging in the place of their choosing through a base funding increase of $57 million across community support service providers, and an additional $150 million funding for home care service providers. Alternative community-based options will be crucial to avoid unnecessary hospitalizations and emergency department recidivism.

b) Embed Care Coordinators formerly based in Ontario's 14 Local Health Integration Networks (LHINs) in primary care and specialist care to promote smoother transition of care between settings.

c) Improve access to self-directed care by expanding the program eligibility to include people living with dementia and their care partners and/or power of attorney.

Recommendation 5

Introduce a flexible fund of $40 million to which long-term care homes across Ontario can apply to implement: (1) an Integrated Care Pathway along with virtual behavioural support models to assess and manage behavioural symptoms; or (2) an emotion-focused model of care, with an overarching objective of promoting person-centred care, decreasing staff absenteeism, improving staff retention as well as addressing behavioural symptoms and reducing hospitalization rates amongst residents living with dementia.

Recommendation 6

a) Invest $1.5 million per year for five years to establish a task force comprised of pharmacists, including Certified Geriatric Pharmacists, which will be tasked with raising awareness amongst healthcare providers about the Beers List medications and the negative impacts of these potentially inappropriate medications on older adults. The purpose of this task force will be to work collaboratively together with primary care physicians, patients and current pharmacies to find safer alternatives, improve patient outcomes and reduce healthcare burden and costs.

b) Build software tools to help identify and flag patients taking potentially inappropriate medications (Beers List) for the task force to target and improve. This would allow pharmacists to better work together with prescribers to reduce the prescribing of inappropriate medications in older adults, many of which cause dementia.

c) Mandate, through the medical and pharmacy colleges (OCPS and OCP), that all prescriptions written and dispensed must include a suggested diagnosis or indication. Most medications can have many potential indications. Providing an indication/diagnosis is crucial to allow inter-professional collaboration, as well as the proper safety and appropriateness assessment of the prescription.

Overview

The Ontario Dementia Care Alliance (ODCA) is a panel of 17 leading experts in dementia care across Ontario, established in December 2022 to advocate for evidence-informed and experience-based recommendations to transform dementia care in our province. An overview of our alliance and its full membership is included in Appendix 1.

There are over 300,000 Ontarians living with dementia today—a number that will triple within the next 30 years. Dementia costs Ontario over $30 billion annually, a figure that will only rise as our population ages and lives longer. Despite the staggering societal and economic impacts of dementia in Ontario, dementia care is reactive, not proactive across the province—leading to inefficient care planning and delivery with knock-on effects for the broader health care system as people living with dementia and their care partners, with nowhere left to turn, have no choice but to seek unnecessary, avoidable, or premature care in resource-intensive hospitals and/or long-term care homes.

The ODCA is concerned that the province does not have an operational dementia strategy and has not identified dementia as a public health priority.[ii] We are encouraged to see the tabling of Bill 121, *Improving Dementia Care in Ontario Act, 2023* which calls for the development of a provincial framework to improve access to dementia care. The ODCA would support the passage of this Bill and asks that the Government of Ontario engage with the ODCA to collaborate and develop comprehensive and standardized models of dementia care.

Around 60,000 Ontarians will be diagnosed with dementia this year—which will increase to 100,000 per year by 2035. Dementia will be among the defining societal challenges Ontario must face in the years and decades ahead, as prevalence and incidence set new highs with each passing year.

We have no time to lose in challenging the status quo of dementia care in Ontario. The ODCA respectfully submits these seven recommendations for consideration in Budget 2024.

Provincial Dementia Care Strategy

Recommendation 1 (a): Develop, implement, and fully fund a comprehensive provincial Dementia Care Strategy, including meaningful targets and outcomes for patient care, care partner supports, and introduction of disease-modifying treatments for Alzheimer's disease.

Recommendation 1 (b): Mandate through legislation, the establishment of a coordinating body within a government agency such as Ontario Health dedicated to overseeing dementia care in all settings, implementing a provincial Dementia Care Strategy, and driving meaningful quality improvements for more consistent patient, care partner, and provider experiences. The coordinating body must have an annualized budget and should have a degree of control over the funding of dementia care services, as determined by the provincial government.

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.

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.

Dementia strategies are recognized by the World Health Organization as important tools for bringing about policy change that leads to improved outcomes. With the introduction of Bill 121 and subsequent support at second reading, Ontario's elected leaders appear to share this recognition of the importance of dementia strategies.

Yet Ontario continues to lag behind other provinces and states in not having a public dementia strategy. This oversight directly contributes to disjointed care and inefficient allocation of constrained health system resources, including staff.

Our recommendations to develop and execute a comprehensive, person-centred provincial dementia strategy would help position Ontario as a leader within Canada on dementia care. Through a legislation, the provincial government can mandate the creation of a new body that can coordinate and calibrate amongst the different Ministries responsible for dementia care as well as the services offered in the province. The government must ensure that the body receives sustained funding and has an annualized budget. The government must ensure that the investments reflect the operational cost of at least 5 FTEs in the first two years, and adjust the budget to account for the coordinating body's expansion over the subsequent years. Most importantly, the government must ensure that the coordinating body has complete oversight and a degree of control over the funding received by dementia care services to ensure it effectiveness.

There are made-in-Ontario models that the province might use to expedite this process.

Cancer Care Ontario was formed after a new provincial framework for cancer care was introduced in the 1990s. Transforming the Ontario Cancer Treatment and Research Foundation into Cancer Care Ontario endowed the province with a more robust and inclusive mandate to enhance cancer services. Additionally, the creation of the Cancer Quality Council of Ontario (CQCO) as an independent health council from the Cancer Care Ontario management has been pivotal in holding the government responsible. The duties of the CQCO include overseeing and publicly reporting on the performance of the cancer system in Ontario, suggesting specific quality enhancements, and providing global comparisons and benchmarks, allowing Ontario to learn from other areas.

Alternatively, the government could consider the example of the Mental Health and Addictions Centre of Excellence which was established within Ontario Health to promote and facilitate the effective rollout of the government's Roadmap to Wellness plan. This Centre is charged with the responsibility for central accountability and supervision for mental health and addiction services; it ensures standardized service quality and delivery, and it develops universal performance metrics and shared frameworks to spread knowledge and establish service standards.

Both models underscore the importance of creating a comparable supervisory entity for dementia care that possesses the authority to track progress, pinpoint deficiencies, and propose recommendations across a range of government services, including health and long-term care.

Inter-Disciplinary Care Model

Recommendation 2: Fund $150 million per year for 10 years to ensure that all Ontarians living with or at risk for dementia have access to team-based primary and specialist care, such that patients with cognitive concerns are assessed within 12 weeks.[iii]

The ODCA believe that cross-sectoral collaboration between family physicians, specialists, and home and community care is critical to promote continuity of care for Ontarians living with neurodegenerative conditions, including mild cognitive impairment, Alzheimer's disease, and other causes of dementia. By removing administrative bottlenecks in the diagnostic pathway, patients will receive more timely care and providers will use their time more efficiently. This efficiency will be crucial in providing early diagnosis, which will be necessary for making effective use of emerging treatment options. By 2028, Canada will be short 44,000 doctors—of which family physicians represent 72 percent.[iv] In Ontario, we barely have half the number of geriatricians needed; just 168 specialists to support over 2.8 million older adults in their complex care needs.[v] Ontario also has a lower-than-average number of neurologists compared to our provincial peers: just 380 of Canada's 1,080 neurologists are based in its largest province.[vi]

This lack of specialist capacity, compounded by family doctors making referrals to specialists due to lack of adequate team-based support for diagnosis, and/or not performing timely initial assessments, accounts for over 90 percent of the projected wait times to receive a diagnosis of Alzheimer's disease in Ontario[vii]. By 2029, bottlenecks between family physicians and specialists will account for 89 months of wait time per patient, on average. The total average wait time by 2029 will be 91 months, or over seven and a half years—longer than many who seek a diagnosis will live.

To overcome the systemic disadvantage of having far fewer dementia specialists than we need, Ontario must make every effort to use their time efficiently—incentivizing primary and specialist care clinicians to work as an integrated team to provide timely access to diagnosis of Alzheimer's disease and other forms of dementia.

This starts with family doctors. These are often the first point of contact for Ontarians with concerns about their cognitive health: family doctors will and must play an increasingly prominent role in dementia diagnosis, by conducting early assessments and, if necessary, facilitating referral to specialists in a timely manner.

Primary care physicians need better support to provide quality dementia care: a report by the Canadian Institute for Health Information (CIHI) found that only 41 percent of primary care doctors felt they were well prepared to manage dementia care in the community, well short of levels reported in comparable nations and 11 points below the Commonwealth average[viii]. Inter-disciplinary models offer this support.

These models have been proven to improve patient outcomes and increase access to diagnostic services initiating assessments for neurodegenerative conditions including mild cognitive impairment and early Alzheimer's disease and ensuring timely access to specialists, where required [ix].

Sustained funding for inter-disciplinary care would expand a proven, efficient model. For the purposes of dementia diagnosis, it is crucial that this model cover both primary and specialist care providers.

The Primary Care Collaborative, a coalition of associations representing frontline care providers including family doctors in various settings, recommends $75 million per year over 10 years to expand access to inter-disciplinary, team-based primary care to all Ontarians.[x] The ODCA expresses its full support for this recommendation.

Team-based care is also a proven model for specialist providers. Annualized funding of an additional $75 million would expand access to team-based specialist care to three-quarters of the province.

Taken together, as these two recommendations must be, this investment would improve outcomes for patients and reduce burden on primary and specialist care providers—improving diagnostic capacity and ensuring Ontarians living with dementia are supported in their desire to age at home, and out of long-term care, for as long as possible.

We therefore urge the government to increase access to team-based primary and specialist care for people living with cognitive disorders to ensure earlier diagnosis, improved access to care, reduced emergency room and hospital visits, delayed admission to long-term care homes, and adequate care partner support.

Dementia Diagnosis

Recommendation 3 (a): Operate existing clinical MRI machines at full capacity to improve monitoring capacity that will be required for forthcoming Alzheimer's disease treatments.

Recommendation 3 (b): Provide coverage under 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 through amyloid beta and tau protein detection, and make preparations to fully utilize expected blood-based biomarker technology.

In May 2023, Health Canada received a submission requesting approval for a treatment for Alzheimer's disease—the first ever such submission in Canada, and the first step in this treatment being administered to Canadians living with mild cognitive impairment or early Alzheimer's disease. This treatment, already approved by US regulators and funded by Medicare, is expected to be the first of several seeking approval in Canada in the near future.

As Canada moves towards its first-ever approved treatment for Alzheimer's disease, three procedures will be crucial to ensure their effective rollout: PET scans, lumbar punctures (LPs) and subsequent CSF analysis, and MRI scans. PET and CSF are, until blood-based biomarkers are approved for the same purpose, the only means by which a definitive diagnosis of mild cognitive impairment/Alzheimer's disease can be obtained. MRI scans would subsequently be required to monitor safety and possible reaction to administered treatments.

Most Ontarians who have been diagnosed with Alzheimer's disease have received a clinical diagnosis, which is a presumptive, but not a biologically confirmed diagnosis. Clinical diagnoses have been shown to be inaccurate about 25 percent of the time for Alzheimer's disease, even in the hands of skilled specialists.[xi] Health Canada has approved confirmatory diagnostics, both PET amyloid scans and CSF biomarker assessments to confirm the diagnosis of Alzheimer's disease, however, neither of these diagnostics are funded in Ontario and as a result the majority of individuals never receive a confirmatory diagnosis of Alzheimer's disease outside of a clinical trial.

A confirmed diagnosis of Alzheimer's disease through PET or CSF assessment and a satisfactory MRI scan will be required for eligibility for these treatments. In order to ensure that patients do not miss treatment opportunities, greater access to MRI scans, PET scans, CSF analysis, and/or future blood-based biomarker testing will be required than is currently available and funded in Ontario.

At a minimum (and nearly all will have a higher total cost), obtaining a diagnosis of Alzheimer's disease will cost OHIP $255 per PET scan, or $150 for a lumbar puncture followed by a variable amount for CSF analysis depending on the biomarkers being tested for. This will be followed by an expected four MRI scans at $73.35 per scan. Without including initial assessments, follow-ups, or specialist appointments, the cost of diagnosis and monitoring MRI scans in the first year following treatment administration will be at least $548.40 per patient. The Alzheimer Society of Ontario estimates a first-year eligibility for Alzheimer's disease treatments in the province of 4,000 patients, requiring an additional 4,000 LPs/CSF analyses or PET scans, followed by 16,000 MRI scans—at a minimum cost of $2.2 million alone, without accounting for the greater cost of specialist appointments and the far greater concern of capacity. These costs, and capacity constraints, will continue to escalate as incidence of dementia surpasses 100,000 per year in Ontario by 2035. [xii]

Research shows that the expected approval of Canada's first-ever approved treatment for Alzheimer's disease will result in an influx of people living with presumed Alzheimer's disease who will seek diagnosis and treatment options.[xiii]

Just as specialist and family physician capacity must be used as efficiently as possible to meet this forthcoming surge in diagnostic demand, so too must scan capacity. This starts with MRI machines, which will see the greatest increase in need with the arrival of treatment options. The Auditor General of Ontario found that the majority of MRI machine operators, as of 2020, are not using their scanners around the clock[xiv] a puzzling under-utilization for a piece of equipment that can cost upwards of $1 million to purchase.

Using these machines 24 hours a day is a cost-efficient way to increase overall capacity, and builds on the government's recent investments to support the addition of new MRI scanners in hospitals across the province—investments which will take up to two years to materialize, and which could be complemented at lower cost by using existing infrastructure around the clock.[xv]

While ultimately the priority outlined in this section is increased access to MRI scans, we also recommend prioritizing daytime appointments (particularly in the late morning to early afternoon) for people living with dementia, who often experience interrupted sleep. Breaks in routine, such as a midnight MRI appointment, can cause days of difficulties for the person and their care partner(s), while also creating the risk of responsive behaviours that prevent the person from receiving a useful MRI scan. No one wants to receive a 3 a.m. appointment, however for people living with dementia this is more than an inconvenience; it is a disruption that will negatively affect their wellbeing, and potentially lead to wasted appointment slots.

The shortage of family physicians and dementia specialists and the limited capacity for biomarker testing indicates that Canada is set to have the "longest and most persistent wait times for a disease-modifying treatment among the G7 countries".[xvi] This is an entirely avoidable situation, and one that can be partially resolved by administrative actions alone.

Currently, PET scans and CSF analysis are not funded through OHIP for diagnosing Alzheimer's disease. This must change before the arrival of disease-modifying treatments in Ontario; without this change thousands of Ontarians will be denied a life-altering treatment, or be forced to travel internationally for a diagnosis.

Fee codes for PET scans and CSF analysis are already established; their applicability must be expanded to include procedures for patients with suspected mild cognitive impairment/early Alzheimer's disease, the population that would most benefit from forthcoming treatments.

With expanded access to PET, Ontario will encounter another barrier to access: availability of radiotracers. These isotopes have a short half-life, requiring to-the-minute precision with both patient and tracer arriving for the scan within a matter of minutes of each other. The logistical challenges involved are immense and call for provincial coordination. Lessons can be learned from the time-sensitive shipment of COVID-19 vaccines, and we urge the government to plan for an uptick in demand for radiotracer shipments in conjunction with expanding access to PET and CSF procedures to cover Alzheimer's disease diagnosis.

The cost and capacity constraints associated with PET scans for diagnosing Alzheimer's disease can be significantly mitigated by making full use of promising blood-based biomarker technologies, if and when they are approved for use in Canada. Late-stage trials underway in the United States have shown exciting results, suggesting a near-future reality in which mild cognitive impairment and early Alzheimer's disease can be detected with near-PET accuracy through a simple, minimally invasive blood test with negligible cost when compared to PET/CSF. We urge the Government of Ontario to prepare for the arrival of blood-based biomarker technology, instructing Ontario Health to draft appropriate use guidelines and an implementation plan so that these technologies can be implemented in Ontario with minimal delay.

Forthcoming treatments for Alzheimer's disease represent a life-altering breakthrough for the millions of Ontarians who will be diagnosed in the coming decades. These treatments alone, however, are only one piece of the puzzle: they must be accompanied by a health care system that enables timely, reliable diagnosis in order for treatments to be administered early, when they are most effective. Maximizing use of existing MRI infrastructure, and expanding access to PET/CSF diagnostic tools, will remove barriers currently in place that would prevent timely access to treatment options—and consequently generate cost savings from avoided hospital and long-term care utilization when these treatments are approved for use.

Home and Community Care

Recommendation 4 (a): Support people living with dementia and their care partners with aging in the place of their choosing through a base funding increase of $57 million across community support service providers, and an additional $150 million funding for home care service providers. Alternative community-based options will be crucial to avoid unnecessary hospitalizations and emergency department recidivism.[xvii]

Recommendation 4 (b): Embed Care Coordinators formerly based in Ontario's 14 Local Health Integration Networks (LHINs) in primary care and specialist care to promote smoother transition of care between settings.

Recommendation 4 (c): Improve access to self-directed care by expanding the program eligibility to include people living with dementia and their care partners and/or power of attorney.[xviii]

Roughly eight percent of long-term care residents in Ontario could have been supported at home if adequate home and community care options been available to them. Yet, most patients living with dementia have few funded options other than long-term care — an expensive, labour-intensive setting intended for individuals with chronic, intensive care needs. Expanding home and community care options provides greater flexibility to meet the needs of health care recipients—promoting patient independence and care partner support while providing cost savings for the provincial government.

To adequately support Ontarians living with dementia in their desire to age in their own home, 2.5 million annual home care visits would be required in this province alone—rising to 4.5 million visits annually by 2040. In 2020, there were just 82,000 home care visits offered to Ontarians living with dementia: a startling gap between supply and demand, and one that results in would-be home care recipients turning to more intensive, less appropriate, and more expensive settings to receive the care they need, often hospitals.[xix]

Older adults who have dementia and live alone at home are twice as likely to transition to long-term care compared to those living with family or personal support services. Similarly, people living with dementia whose caregiving support becomes unavailable are also twice as likely to enter long-term care.

This is despite the fact that 96 percent of older adults living in Ontario want to stay and age in their own home for as long as possible.[xx] In addition to being the preferred choice for many older adults, home care is less expensive when compared to its alternatives: $45 per day, versus $142 per day in a long-term care home and upwards of $1,000 per day for a hospital bed.[xxi]

To address these issues there is a need to establish and broaden integrated community-based care options, which encompass a range of services such as community support, day programs, respite care, home care, and occupational therapy. This approach aims to maintain the quality of life for individuals living with dementia. Expanding availability of community-based care across all regions of the province would enable clients to receive the right care, at the right time, in the right place—improving both patient outcomes and system efficiency. An important first step for the government would be to provide a base funding increase for community support services while increasing its funding to home care providers.

In addition to much-needed funding, we encourage the Ministry of Health to embed Care Coordinators formerly placed within the province's 14 LHINs in primary and specialist care settings, along with expanded care options and enhanced eligibility criteria to address the challenges of organizing home care for people living with dementia, and to promote smooth transitions between and within health service providers.

Continuity of care is crucial in dementia care: embedding care coordination within the primary and specialist care settings most frequented by older adults living with neurodegenerative conditions including Alzheimer's disease and other causes of dementia, who are among the most frequent and complex consumers of health care in Canada, would position these staff closer to the clients who most need them.

This move would also reduce the current administrative burden by reducing duplication of roles and date, and complement the access to interdisciplinary care recommended previously. Expanded eligibility criteria would allow physicians to integrate clinical observations and foster improved service delivery at a lower cost. This would provide more accurate information to the client about available services, based on their clinical needs instead of eligibility deduced through algorithms.

Ultimately patients themselves, as well as their care partners, are the leading experts in their own care. Despite this, Ontario is one of the few provinces that does not offer self-directed care funding to people living with dementia: overly restrictive eligibility criteria, specifically the preclusion of care partners managing self-directed care funding on their supported person's behalf (a restriction not in place in any other province), unfairly and unjustifiably precludes people living with dementia from accessing this flexible care option.[xxii] Removing this restriction would expand a worthwhile and patient-centred care option to cover hundreds of thousands of additional patients, providing additional options for them to age in their own home—delaying or avoiding admission to long-term care.

Long-Term Care

Recommendation 5: Introduce a flexible fund of $40 million to which long-term care homes across Ontario can apply to implement: (1) an Integrated Care Pathway along with virtual behavioural support models to assess and manage behavioural symptoms; or (2) an emotion-focused model of care, with an overarching objective of promoting person-centred care, decreasing staff absenteeism, improving staff retention as well as addressing behavioural symptoms and reducing hospitalization rates amongst residents living with dementia.

The ODCA believes that there is an urgent need to transform the way dementia care is delivered in long-term care homes to improve quality, reduce variation, and where possible prevent visits to hospital emergency departments and subsequent admissions. We therefore recommend that the Government of Ontario introduce flexible funding to which homes can apply to implement either (1) an Integrated Care Pathway (ICP) for dementia along with the integration of virtual behavioural support models; and/or (2) emotion-focused models of care to reduce emergency department visits and address behavioural symptoms.

We believe that homes would benefit from having both of these components; however, cognizant of the challenge in changing models of care, we propose that homes apply to implement one out of the two as a first step.

The Dementia ICP is a model of care that has been extensively evaluated by members of the Toronto Dementia Research Alliance. The Alliance had initially proposed the implementation of an Integrated Care Pathway (ICP) in 30 long-term care homes across the Greater Toronto Area. The ICP aims to standardize the assessment and management of behavioural symptoms in people living with dementia. The ICP can be delivered and administered by physicians, nurses, and personal support workers (PSWs). Agencies and organizations such as Ontario Health, Behavioural Supports Ontario, and the Alzheimer Society will support long-term care homes to sustain symptom management.

The anticipated benefits of the ICP include reduced behavioural symptoms, improved quality of life, decreased polypharmacy, lower fall risks in a geriatric mental health inpatient unit, reduced care partner burnout, fewer hospitalizations, and lower rates of Alternate Level of Care (ALC) designation.

If aggression and agitation persist amongst patients after following the ICP, long-term care homes can shift from the ICP to virtual behavioural support models.[xxiii] Successful models, specifically Virtual Behavioural Medicine, consist of a team of specialists, including behavioural neurologists, neuro-psychiatrists, nurses, pharmacists, mental health professionals, and the Behavioural Supports Ontario (BSO) team to provide support in the management of responsive behaviours.

Through the fund, long-term care homes could also apply for funds to implement emotion-focused models of care, such as the Butterfly or Green House model, that prioritize addressing not only residents' physical needs but also their emotional well-being. Bringing about this cultural transformation in long-term care facilities requires the province to move away from a narrow emphasis on tasks related to residents' fundamental needs and physical health, such as feeding and bathing. Instead, it involves adopting a person-centered approach that extends to encompass the emotional well-being, relationships, and overall quality of life of the residents.

Emotion-focused care is a cost-effective strategy that could lead to significant enhancements in various aspects of long-term care and potentially reduce expenses related to staff turnover and resident hospitalizations. For instance, the implementation of the Butterfly model typically costs $200,000 to cover the one-time costs of training, capital, and transitioning and $100,000 per year in annual operating costs to support homes that have made this transition.

Our recommendation is consistent with the federal government’s national dementia care strategy, *A Dementia Strategy for Canada: Together We Aspire,* which include "identifying and adopting best practices, proven innovations and strategies that enhance integrated dementia care, focused on the safety, quality of care and quality of life of people living with dementia in long-term care.” [xxiv]

Appropriate Prescription of Medications

Recommendation 6 (a): Invest $1.5 million per year for five years to establish a task force comprised of pharmacists, including Certified Geriatric Pharmacists, which will be required to raise awareness amongst healthcare providers about the Beers List medications and the negative impacts of these potentially inappropriate medications have in older adults. The purpose of this task force will be to work collaboratively together with primary care physicians, patients and current pharmacies to find safer alternatives, improve patient outcomes and reduce healthcare burden and costs.

Recommendation 6 (b): Build software tools to help identify and flag patients taking potentially inappropriate medications (Beers List) for the task force to target and improve. This would allow pharmacists to better work together with prescribers to reduce the prescribing of inappropriate medications in older adults, many of which cause dementia.

Recommendation 6 (c): Mandate, through the medical and pharmacy colleges (OCPS and OCP), that all prescriptions written and dispensed must include a suggested diagnosis or indication. Most medications can have many potential indications. Providing an indication/diagnosis is crucial to allow inter-professional collaboration, as well as the proper safety and appropriateness assessment of the prescription.

In Canada, two out of every three hospitalized seniors are given medications that are ill-suited for older adults, leading to a heightened risk of injuries and adverse reactions caused by these drugs.[xxv] Research reveals that 37 percent of seniors filled prescriptions not recommended for those over the age of 65.[xxvi] Many patients are often prescribed anticholinergic drugs, which lead to an elevated risk of Alzheimer's disease and other forms of dementia.[xxvii] Furthermore, the cumulative impact of these medications exhibits a dose-dependent relationship with the risk of developing dementia.

The financial impact of inappropriate prescriptions on the Canadian healthcare system is substantial. An estimated cost of $1.8 billion is attributed to the repercussions of these prescriptions, which encompass hospitalizations stemming from falls and fractures.[xxviii] Moreover, approximately $400 million is expended annually in Canada on prescriptions that are deemed potentially inappropriate according to the standards set under the Beers Criteria.[xxix]

It is therefore important to enable pharmacists to conduct routine medication audits for patients. Pharmacists can use their specialized knowledge to review prescriptions and identify potential improvements. By establishing a digital platform that enables a collaborative medication review, doctors can focus on accurate diagnoses, while pharmacists contribute their expertise to recommend appropriate medications. This approach would not only improve patient care but also streamline communication between healthcare professionals. Over time, this initiative can lead to a more comprehensive and personalized approach to medication management.

Conclusion

The ODCA's vision is an Ontario where dementia care is complete care. It is person-centred throughout all aspects of a person's dementia journey, including prevention mechanisms, timely diagnosis, early care and appropriate solutions for care partners – where dignity and independence are valued and nurtured, and where quality of life is maintained until end of life.

Forthcoming treatment options for Alzheimer's disease offer hope to the millions of Ontarians who will be diagnosed over the coming decades. This hope will quickly turn to despair, then anger as these same Ontarians become aware that their government did not prepare to get life-altering treatments to them in time.

The recommendations made in this document will make immediate improvements to the quality of life of people living with dementia and their care partners, the quality of care and resulting job satisfaction from providers, and to the health system's ability to quickly detect and diagnose neurodegenerative conditions such as mild cognitive impairment and early Alzheimer's disease.

We, the 17 expert members of the Ontario Dementia Care Alliance, stand behind these recommendations—and stand ready to partner with government in our shared goal of offering Ontarians living with dementia and their care partners the right care, at the right time, in the right place.

The status quo of dementia care isn't working; let's work together to do better for Ontarians living with dementia, their care partners, and health care providers.

Appendix 1: About the Ontario Dementia Care Alliance

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 will 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.

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Expert members of the ODCA are:

1. **Dr. Sandra Black, OC, O. Ont., MD, FRSC:** Senior Scientist, Sunnybrook Research Institute; Brill Chair in Neurology, Department of Medicine, University of Toronto and Sunnybrook Health Sciences Centre.
2. **Dr. Michael Borrie, MB, ChB, FRCPC:** Head, Department of Geriatric Medicine, Parkwood Hospital; Professor, University of Western Ontario Schulich School of Medicine and Dentistry, Department of Medicine, Division of Geriatric Medicine.
3. **Dr. Sharon Cohen, MD, FRCPC:** Medical Director and Site Principal Investigator, Toronto Memory Program.
4. **Andy Donald, RPH, MSc:** Founder and CEO, The Health Depot Pharmacy.
5. **Dr. Morris Freedman**: MD, FRCPC: Professor, Department of Medicine (Neurology), University of Toronto; Head Division of Neurology and Medical Director Pamela and Paul Austin Centre for Neurology and Behavioural Support, Baycrest Health Sciences; Scientist, Rotman Research Institute, Baycrest
6. **Deb Galet:** Vice President, Long-Term Care and Ambulatory Care & Chief Heritage Officer, Baycrest.
7. **K. Jennifer Ingram MD FRCPC D.Sc.(hon):** Founder, Kawartha Centre—Redefining Healthy Aging; Adjunct Professor, Trent University, Trent Centre for Aging and Society; Consulting Geriatrician to Seniors Care Network; Co-Lead - Primary Care Embedded Memory Services.

8. **Dr. Linda Lee, MD, FCFP:** Founder, MINT Memory Clinics; Schlegel Chair in Primary Care for Elders, Research Institute for Aging.

9. **Lisa Levin:** CEO, AdvantAge Ontario.

10. **Adam Morrison:** Director, Policy and Planning, Provincial Geriatrics Leadership Ontario.

11. **Dr. Tarek Rajji, MD:** Chair, Medical Advisory Committee, Centre for Addiction and Mental Health; Professor of Psychiatry and Director of Geriatric Psychiatry Division, and Executive Director, Toronto Dementia Research Alliance, University of Toronto

12. **Dr. Lisa Saksida, PhD, FCAHS, FRSC:** Professor and Canada Research Chair in Translational Cognitive Neuroscience, University of Western Ontario Schulich School of Medicine and Dentistry; Co-Scientific Director of the BrainsCAN Canada First Research Excellence Fund Program in Cognitive Neuroscience, University of Western Ontario.

13. **Dr. Rick Swartz, MD, PhD:** Staff Neurologist, Sunnybrook Health Sciences Centre; Associate Professor, University of Toronto Faculty of Medicine.

14. **Laura Tamblyn Watts, LLB:** Founder and CEO, CanAge.

15. **Barbara Tarrant:** Care partner.

16. **Dr. Carmela Tartaglia, MD, FRCPC:** Marion and Gerald Soloway Chair in Brain Injury and Concussion Research; Associate Professor, Tanz Centre for Research in Neurodegenerative Diseases, University of Toronto.

17. **Dr. Jennifer Walker, PhD:** Senior Core Scientist and Indigenous Health Lead, ICES; Canada Research Chair in Indigenous Health, Laurentian University; Assistant Professor, Dalla Lana School of Public Health, University of Toronto.

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