Alzheimer Society

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Roadmap Towards a Renewed Ontario Dementia Strategy

Expert Panel Analysis

Submitted by the Alzheimer Society of Ontario

"Those with dementia are still people and they still have stories and they still have character and they're all individuals and they're all unique. And they just need to be interacted with on a human level."

- Carey Mulligan

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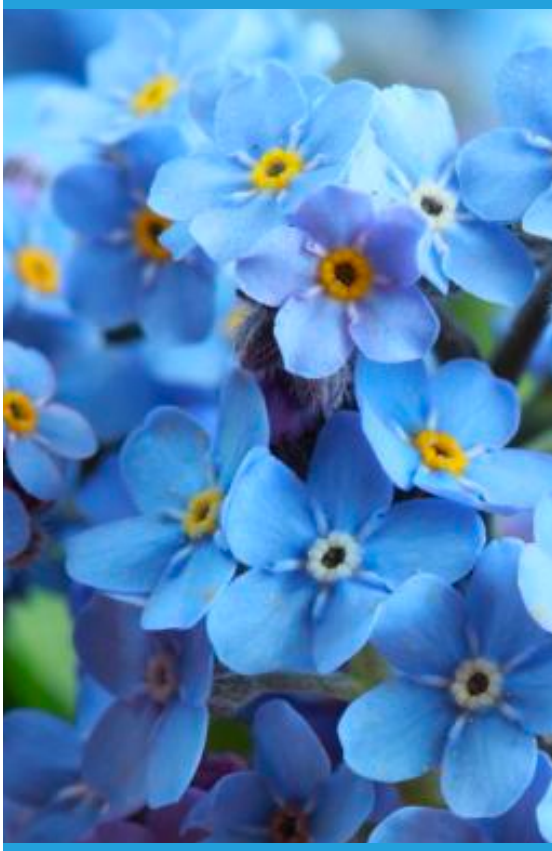
Acknowledgements

In-depth interviews were conducted with expert panelists over a three-month period to identify opportunities and challenges in delivering quality and accessible dementia care in Ontario. This expert panel consists of healthcare professionals, community organization experts, people living with dementia, care partners, and other stakeholders within dementia care.

Graciously offering their time, expertise, and compassion, this group of renowned experts illuminated future achievable and non-partisan priorities required to reduce barriers, support aging and care-at-home strategies, build cost efficiencies, and increase access to compassionate made-in-Ontario dementia care.

This **Roadmap Towards a Renewed Ontario Dementia Strategy** reflects the career and lived experiences of panelists and presents a collective **goal of ensuring that people living with dementia preserve their dignity and maintain their quality of life until end of life.**

Gratitude is extended to all panellists who contributed to this **Roadmap Towards a Renewed Ontario Dementia Strategy**. To respect privacy, not all contributors are listed. In honour of partners who give of themselves every day, this plan has been created with thanks to those who work behind the scenes without public credit, as well as the following industry experts:



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Executive Summary

Ontario Premier Doug Ford has prioritized quality of life issues for older Ontarians since winning a majority government during Ontario's most recent provincial election on June 7, 2018.

We applaud steps the provincial government has taken in recent years to reduce silos within healthcare and focus care where it should be: on the patient. A patient's needs, and not those of the healthcare system, must guide every care decision made for Ontarians living with dementia. This must include respecting every person's individuality and independence.

The previous government committed $100 million over three years for an Ontario Dementia Strategy in 2017. The Minister of Health and Long-Term Care at the time initiated a consultation process for developing this strategy, and the former government acknowledged that the costs for dementia care in Ontario would be nearly $325 billion from 2008 to 2038.[i]

Unfortunately, much of the former government's plan and promised investments did not come to fruition. A lack of key investments promised in 2017 have created further gaps within dementia care. It is estimated that almost one million Canadians will live with dementia soon after 2030.

As baby boomers continue to age and retire, prevalence of dementia will continue to rise at an alarming rate.

Currently, over 260,000 Ontarians live with dementia. As Ontario's population ages, the number of people living with Alzheimer's disease and other forms of dementia is expected to double within a generation.

We respectfully call on the Government of Ontario to keep existing momentum by expanding funding and supports for people living with and those affected by dementia.

Building on Canada's first-ever national dementia strategy, unveiled in 2019, our panel of experts from across the province proposes this updated and achievable **Roadmap Towards a Renewed Ontario Dementia Strategy.**

Our expert panel's recommendations for a renewed Ontario Dementia Strategy encompass care for people living with dementia, including for their care partners, throughout the dementia journey. From early diagnosis to end of life, this strategy focuses on prolonging compassionate and familial care at home.

Dementia care is currently centred around institutional settings: hospitals and long-term care. Through our achievable strategy, we propose a shift in focus which keeps older Ontarians living with dementia where they want to be — at home — for as long as possible.

Our reasons are threefold.

First: Most people living with dementia prefer to remain in their community and out of long-term care homes for as long as possible. In fact, this helps preserve their quality of life.

Opinion data from a survey conducted by the Alzheimer Society of Ontario (ASO) in 2022 found that almost 90 percent of all Ontario voters feel their government should be doing more to help older Ontarians stay at home for as long as possible—a figure that did not vary by party support. This is a non-partisan and universally supported proposition.

Second: Supporting aging in place will reduce unsustainable capacity shortages faced by long-term care homes and hospitals.

Despite the laudable investments and commitments to long-term care made by the current government, building new beds alone will not address severe capacity constraints.

Third: Redirecting public funds to support aging in place will be more cost-effective for the government over the next four years.

In 2020, the province estimated that the cost to provide home and community care was $103 per day. This is in comparison to $201 per day for providing services in long-term care, with the number surging to $730 per day for alternate level of care (ALC) patients in hospitals.[ii]

People living with dementia are more likely to be admitted to long-term care homes than those without dementia. It is common for people living with dementia to require more care and services from the healthcare system, including additional family physicians and specialist appointments, home care visits, hospitalizations, and emergency department visits.

Our panel respectfully requests and offers a compassionate, cost-effective, and proactive approach to long-term care, rather than the current reactive model. Government, care partners, and industry must consider collectively moving away from the tangible indicators of care for the elderly, such as building more infrastructure in the long-term care sector. Proactive provision of services, following a standard care pathway for Ontarians living with dementia, will offer earlier detection, prolonged aging at home, increased dignity, compassion, and a cost-effective streamlining of service care.

Ontario's experts in dementia care recommend that the provincial government:

Draft and implement a renewed Ontario Dementia Strategy under the purview of a dedicated Secretariat, with the authority to oversee dementia care and make recommendations across the spectrum of government services, including health and long-term care.

Establish integrated community-based care, encompassing community support services, day programs, respite care, home care, memory clinics, occupational therapy, and medical interventions to retain the quality of life of people living with dementia.

Complement the current plan of expanding long-term care homes and building of new long-term care beds by ensuring that the sector has sufficient health human resource capacity and well-trained staff to provide adequate care for older Ontarians, particularly dementia care and behavioural support.

This **Roadmap Towards a Renewed Ontario Dementia Strategy** addresses issues faced by people living with dementia, including acknowledging that a dementia journey begins at the pre-diagnosis stage. There are forward-thinking options to bolster our educational infrastructure for healthcare professionals. This roadmap introduces risk reduction measures that can help delay onset and reduce severity of symptoms, prolonging an individual's ability to live with dignity at home.

These recommendations address bottlenecks in service provision that will be resolved through straightforward policy changes, as well as those requiring future investment.

Some recommendations may initially seem overarching and include aspects of seniors' care that are not specific to people living with dementia. Yet, these well-rounded investments would result in both cost-savings and better quality of life for all older Ontarians who utilize these services, including people living with dementia and their care partners. The proposed budget is based on recommendations from our partners in dementia care, and the historic investment levels already provided by the provincial government.

Through their collaboration, experience, and findings, panelists recommend leveraging existing primary care, non-clinical services, and community support services for people living with dementia to support aging in place across all regions of Ontario.

Currently, most available services are concentrated around urban Ontario. Ontario must expand its reach to ensure equitable access to dementia care across all the regions of the province.

Our strategy draws attention to the unsung heroes of dementia care: care partners. Currently, many dementia care professionals unfortunately perceive home care as an offloading of government responsibility to care partners, given that the province does not offer them adequate and timely support. While care partners prefer to provide care at home, they can only do so with sufficient support from the government. But 34 percent of care partners find it challenging to receive care at home while 56 percent of them struggle to balance caregiving duties with other responsibilities.[iii]

Collectively, decision makers must shift perception to recognize and accept that support for care partners is an important component of an individual's dementia care journey. Encouraging aging in place, the panel also considers what is required to reduce the strenuous emotional, physical, spiritual, and financial burden placed on care partners.

The objective of the **Roadmap Towards a Renewed Ontario Dementia Strategy** is to work collaboratively with government, industry, care providers, families, and people living with dementia to buffer the economic and emotional impact of dementia on Ontario's health and long-term care systems in the coming decades.

Educational Infrastructure

Ontario's 14,000 physicians are often the first and main source for discussing and diagnosing dementia. Yet, many physicians currently receive limited education and training for neurology, let alone for dementia diagnosis and care.

Headaches and delirium are the two most common reasons for hospitalization, yet a new generation of doctors are not receiving medical training pertaining to the brain.

For example, when trainees in neurology go through their rotations, they are not mandated to spend time in a community clinic to learn all the practical aspects of care. Additionally, the existing curriculum does not even have minimum standards across all disciplines that touch upon dementia.

The insufficient understanding of dementia care and the lack of knowledge of how to work with people living with dementia is evident amongst other professionals and front-line health and related workers including nurses, social workers, personal support workers (PSWs), and staff in long-term care homes—and this extends to care partners as well.

CEO of AdvantAge Ontario Lisa Levin suggests incorporating "an emotion-focused approach to care" into the training of health professionals who work closely with people living with dementia.

Considering the prevalence of the disease, dementia care needs to be a well-integrated part of training programs for healthcare professionals.

From an equity and inclusion perspective, the most used models of care lack training and tools to improve cultural competencies. These are integral in considering the regional, linguistic, religious, and spiritual nuances to better support the diverse population of Ontario.

PANEL RECOMMENDATIONS:

1. Create mandatory professional development for physicians regarding neurology, dementia diagnosis and emotion-focused care, bundled as comprehensive components of education, training, and professional development for physicians in Ontario.[iv]

2. Ensure that personal support workers (PSWs) receive mandatory education and training for person-centred and emotion-focused dementia care.[v]

3. Provide routine and standardized online or in-person training to physicians, PSWs, social workers, long-term care staff and other professionals that support people living with dementia to ensure that they are updated on best practices for dementia care based on the latest research and findings.[vi]

4. Mandate dementia-specific training as a requirement for healthcare professionals to receive continuing education credit (CEC) or renewed licenses.

5. Require healthcare professionals to receive training on socio-economic and cultural considerations to provide better dementia diagnosis and treatment plans.

6. Partner with local Alzheimer Society offices to offer informative programs on dementia care to care partners after diagnosis to facilitate timely advance care planning, supporting aging in place, and reduce capacity constraints in hospitals and long-term care homes.

SUMMARY OF INVESTMENTS

Leveraging the Government of Ontario's February 2022 $4.1 million investment in PSWs, commit an additional **$10 million** for the training and recruitment of 1,000 new PSWs at public career colleges in Ontario through a new PSW Challenge Fund.

Support the Alzheimer Society of Ontario with a 20 percent increased investment of **$600,000** to offer programs, such as **Finding Your Way®** and **Building Dementia-Friendly Communities™**, to professionals and care partners.

Quality Standards for Dementia Care

In 2015-2016, Ontario's 14 local health integration networks (LHINs) reported that the proportion of people living with dementia who received home care services varied from 52 percent to 62 percent across the province.[vii]

Additionally, the average number of hours for personal support and homemaking services was between 93 and 179 hours per client, highlighting the need to establish quality standards for dementia care to ensure equitable access across the province.[viii]

Moreover, clients living with dementia do not have continuity of care throughout their dementia journey. They often alternate between geriatricians, physicians, and neurologists for assessments and treatment planning. Without standard IT infrastructure and routine coordination amongst healthcare professionals, treatments will continue to deviate away from a client-centred plan.

Currently, Ontario does not have a clear dementia pathway for both people living with dementia and their care partners. Christina Stergiou-Dayment, Senior Director, Provincial Programs and Partnerships at the Alzheimer Society of Ontario suggested that like Cancer Care Ontario, our province needs a standard, easy-to-follow pathway for individuals living with dementia who begin interacting with the healthcare system throughout their journey, including pre-diagnosis. There should be specific, time-indexed steps with a focus on obtaining a clinical assessment, consideration of diagnostic options, review of potential pharmaceutical interventions, and a plan for accessing home and community supports.

As with cancer and other widely prevalent diseases, a diagnosis of dementia should lead to answers, not more questions. The client should be told what to expect at every stage, and there must be systems in place to meet these expectations.

Ms. Stergiou-Dayment says that the Health Quality Ontario (HQO) standards for dementia can act as a guiding framework for early detection and assessment. The HQO standards focus on ten aspects, including comprehensive assessment and diagnosis, access to interprofessional care teams, creation of individualized care plans, access to primary care, and support for care partners.[ix]

Additionally, each of these standards have measurable performance indicators that help assess the quality of care provided and set a benchmark for improvement.

This can also help professionals to focus on a standardized approach rather than a standardized care plan. At a provincial level, a standardized approach should be used to ensure that people living with dementia have access to all the clinical, non-clinical, and community services that are dementia-specific.

Setting standards would help professionals in primary care consider assessment instead of concluding with a diagnosis. However, we need to avoid a standardized care plan for all dementia clients to ensure that their unique needs are met.

PANEL RECOMMENDATIONS:

1. Establish a clear Dementia Pathway including a presumptive diagnosis, assessment of suitable pharmaceutical and non-pharmaceutical interventions, support through clinical and non-clinical services, and clear management guidelines.[x]
2. Adopt Health Quality Ontario (HQO) standards for dementia, to ensure equitable access to clinical and non-clinical services for people living with dementia and their care partners, while respecting their human rights and dignity.[xi]

SUMMARY OF INVESTMENTS

These are qualitative improvements.
As such, no specific financial investment is required.

Primary Care

Canadians receive 90 percent of their medical care through primary care.

Primary care is the backbone of our province and country's healthcare system. Most people living with dementia can be managed effectively and efficiently with dignity and compassion in primary care if they receive a combination of both supportive and well-trained primary care services and a range of housing and community support.

Apart from the lacking educational infrastructure to support dementia care, Ontario does not have an adequate remuneration system for Care of the Elderly (COE) physicians. Unfortunately, this disincentivizes family physicians from specializing in elder care.

Family physicians also face additional barriers in providing quality dementia care. This includes limited support from specialists, low public coverage of dementia drugs, and insufficient time to meet the necessary hours of clinic visits.

Establishing physician payment fee codes would aid in incentivizing physicians to move towards dementia care.

Fee codes also help with monitoring the prevalence of dementia amongst Ontarians. Currently, cases are being under-reported by as much as 50 percent since existing physician billing and fee codes do not capture people living with dementia.

PANEL RECOMMENDATIONS:

1. Establish time-based fee codes for initial assessment and routine follow-ups to improve the remuneration model for Care of the Elderly physicians, increase primary care capacity for dementia care, and improve monitoring of dementia-related cases in the province. Establish a similar model for physicians attending to people living with dementia in long-term care homes.

2. Offer Alternative Payment Plans (APP), which lay out the salaries, incentives, and after-hour bonuses and rewards for physicians, nurse practitioners, and other clinical staff specializing in care of the elderly to improve primary care capacity across the province, especially in rural Ontario.

3. Set up standardized IT infrastructure, including hardware and software, and ensure sufficient training for these tools to facilitate a hybrid model of clinic visits for regular assessment of people living with dementia.

SUMMARY OF INVESTMENTS

Investment of **$10 million** to increase access to primary care, by incentivizing physicians to diagnose, assess, and conduct routine follow ups for people living with dementia.[xii]

Ensure that the government's commitment of nearly **$4 billion** to connect all regions in the province to high-speed internet also expands to primary care facilities to facilitate a hybrid model of dementia care.

Diagnostic Capacity

Christina Stergiou-Dayment, Senior Director, Provincial Programs and Partnerships at the Alzheimer Society of Ontario says that early detection is the gateway to better outcomes and cost-effective management. This also enables earlier conversations on advanced care planning.

The province not only has limited services for screening, assessment, and diagnosis, but also for treatment thereafter. A more in-depth diagnostic capacity is essential: the ability to have greater specificity at the time of diagnosis will allow specialists to address the presentation of unique needs to provide appropriate routine medical management.

Family physicians can draw upon expertise from other healthcare providers. For instance, specialists can conduct specialized tests for diagnosis, social workers excel at providing a plan for care partners, and pharmacists can offer insights into better management for the prescription of medicines.

Family physicians rely on geriatricians for diagnosis and treatment plans but face challenges owing to long wait times. Establishing virtual diagnosis for geriatric clinics can reduce the wait time and allow the physician to start planning properly.

It is important to consider referrals for specific services, providing information about substitute decision-making and powers of attorney for people living with dementia, connecting them to local Alzheimer Societies, and identifying continuing care options such as home-based support, alternative housing and care options or long-term care. Yet, these are not always part of the diagnosis process.

But these factors all play an important role in ensuring quality of life along the dementia journey.

Physicians should be encouraged to connect people living with dementia to **First Link® Care Navigation** immediately after diagnosis, and this referral process should be made as seamless as is practical. Physicians often find it challenging to identify First Link® Care Navigators that are within close vicinity to clients. This is due to inequitable access of Navigators along with existing technological limitations.

It is also important to note that multimorbidity is highly prevalent amongst people living with dementia. In fact, more than one-third of people living with dementia have five or more chronic conditions, which often increases the probability of hospitalization and emergency department (ED) visits.[xiii]

PANEL RECOMMENDATIONS:

1. Propose assessments of brain health in routine health checks to identify mild cognitive impairment to facilitate early dementia diagnosis.[xiv]

2. Inclusion of checkups and assessments of older Ontarians above the age of 60, when mild cognitive impairment is likely to appear, in the best practices for dementia diagnosis

3. Highlight the importance of presumptive diagnosis over complete diagnosis to encourage physicians to carry out early assessment.

4. Inclusion of assessment for possible multimorbidity during dementia diagnosis to allow for greater specificity in the dementia care plan.

5. Develop dementia-specific tools within advanced care planning (ACP) such as providing information about substitute decision-making and powers of attorney, as well as the process for applying to long-term care homes. Include ACP in the best practices for dementia diagnosis.

6. Encourage research of dementia diagnosis through blood biomarkers, cerebrospinal fluid biomarkers, and retinal scans while developing a strategy to expand these services over the next five years.

7. Improve infrastructure by providing commonly used diagnostic tools such as magnetic resonance imaging (MRI) and positron emission tomography (PET) scans and ensure that OHIP covers these expenses.

SUMMARY OF INVESTMENTS

Increase capacity of PET scan centres in Sudbury, Hamilton, London, and Toronto with an investment of **$10 million** in 5 centres.[xv]

Support more Ontarians living with dementia, their care partners, and families with an investment of **$3.26 million** in First Link® Care Navigation.[xvi]

Specialist Care

Specialists for the diagnosis and treatment of dementia are distributed amongst three groups: 1) neurologists, 2) geriatricians, and 3) geriatric psychiatrists. Amongst geriatricians and geriatric psychiatrists, only a small proportion specialize in dementia care.

Specialist care is insufficient in Canada and Ontario. In 2019, a study reported that our country had 376 geriatricians and 354 care for the elderly (COE) physicians; Ontario reported 168 geriatricians.[xvii]

It was further estimated that Canada currently has a shortage of 471.7 geriatricians (based on the commonly used benchmark of 1.25 geriatricians per 10,000 seniors aged 65 years or older).[xviii] A complete diagnosis from specialists is necessary to open access to treatments specific to their needs. Still, Ontarians typically wait for six to nine months to receive this certainty.

Geriatricians and specialists work best in a collaborative and integrated team, which includes occupational therapists (OT), physiotherapists (PT), social workers, nurses, and mental health workers.

Yet most geriatric team comprised of various health disciplines are employed by hospitals and Provincial Geriatrics Leadership Ontario (PGLO) on a contractual basis, leading to inconsistency in interprofessional teams. The health human resource challenges that specialists face in Ontario limit their capacity to provide appropriate routine medical management.

PANEL RECOMMENDATIONS:

1. Ensure that geriatric clinics have access to occupational therapists (OT), physiotherapists (PT), social workers, and nurses to allow for consistency within the interprofessional teams.
2. Increase compensation and provide permanent employment contracts to occupational therapists (OT), physiotherapists (PT), social workers, and nurses.
3. Initiate a collaboration between PGLO and Ontario Health to improve the accessibility of services including, but not limited to, assessment, diagnosis, and treatment planning across all medical complexities.
4. Establish funding models to expand geriatric services, to encourage physician trainee recruitments to geriatric and neurology services.

SUMMARY OF INVESTMENTS

Annual **$15 million** investment to create and expand interprofessional teams in geriatric clinics across the province.[xix]

Coordinated Care

Equitable and consistent access to care for people living with dementia across their dementia journey is essential in retaining quality of life. Continuity of care is important for optimizing patient outcomes. Achieving greater continuity of care requires improvements in the coordination of care.

In addition to clinical services, a coordinated provision of the following services will ensure that people living with dementia can remain in their homes and communities for longer:

Non-clinical services:

- Memory clinics
- Respite care
- Meal programs

Community Support Services (CSS):

- Supportive housing
- Adult day programs
- Transportation services

Home Adaptations:

- Accessibility and orientation aids
- Monitoring technology

Along with existing human health resource challenges in dementia care, current professionals in this space often operate in silos. Practitioners must be better integrated to promote greater continuity of care. These services must be available and linked to screening and assessment along the dementia pathway.

Additionally, Ontario's current system lacks the IT infrastructure to provide better coordination and information dissemination amongst physicians, specialists, care partners, and service providers. A common interface that links all the settings of care and their care partners will be a good first step to improve coordination.

PANEL RECOMMENDATIONS:

1. Ensure that people living with dementia receive coordinated care, by improving access to clinical services, non-clinical services, community support services, and home adaptations.
2. Improve IT infrastructure, to embed referrals within electronic medical records (EMR) systems and ensure that healthcare professionals have sufficient training for using the systems to connect with CSS and non-clinical services.

SUMMARY OF INVESTMENTS

Investment of **$20 million** in EMR projects and other e-tools to support diagnosis and continuity of care, at the point-of-care.[xx]

Aging in Place

The number of Canadians living with dementia (aged 65 or older) who stay in their own homes is expected to increase from 55 percent (2008) to 62 percent (2038),[xxi] highlighting the need for a sufficient supply of adequate home care.

The focus of aging in place should be on "ablement" instead of "disablement". Ontario should be creating homes and communities for people living with dementia to succeed. In 2020, there were 82,000 home care visits to Ontarians living with dementia — a significant gap in capacity versus demand, with an estimated 2.5 million annual home visits being needed to support people living with dementia. This number is expected to increase to 4.5 million annual visits by 2040, as the number of people living with dementia increases to 1.1 million.

Many care partners believe that the home care system is centred around an algorithm that is primarily based on physical infirmity or complexity. There is an eligibility criterion for neurodegeneration and how much transportation and home care services clients living with dementia will need. Additionally, if the individual has a care partner at home, the province may rule out the provision of home services in some cases. Unfortunately, and understandably, care partners to an older Ontarian living with dementia report greater degrees of distress (45 percent) than the general care partner population (26 percent).[xxii]

Home care support can include assistance for regular activities that support dignity such as eating and bathing.

A significant barrier to the adequate supply of home care services is the recruitment and retention of home and community care staff. On average, salary levels for PSWs in home and community care settings are 19 percent less than PSWs in hospitals and 9 percent less than those in long-term care homes.[xxiii] On average, PSWs in home and community care earn around $17 per hour. [xxiv] These lower wages lead to a continuous movement of human resources away from home and community care services, and presents a major barrier to home and community care providers when seeking to fill vacant positions. Ontarians recognize that the pay disparity for healthcare workers filling similar roles in different settings is fundamentally unfair: 2022 opinion polling conducted by the Alzheimer Society of Ontario found that 82 percent of voters either support or strongly support bringing home and community care compensation in line with the hospital and long-term care sectors.

Community organizations play an important role in supporting people living with dementia in their desire to age at home. In a 2021 study completed by 1,900 Alzheimer Society clients, 30 percent stated that the support they received from the Society helped avoid a hospital visit. On average, respondents said 2.1 hospitalizations were avoided thanks to Alzheimer Society services. This is also true in long-term care, with 40 percent of care partner respondents saying that supports and services from the Alzheimer Society helped them keep their supported person at home for, on average, 1.38 years longer before a transfer to long-term care, than if those services had not been accessible.

Access to memory clinics can also help people living with dementia delay admission into long-term care homes. A 2019 evaluation of the MINT Memory Clinic model specifically, commissioned by the then-Ministry of Health and Long-Term Care, found that emergency department costs were halved for those connected to the clinic. The study also found an average delay of six months for entering long-term care homes compared to those not supported through a MINT Clinic.[xxv]

Cross-sectoral collaboration between primary care, specialist care, and community care, including the Alzheimer Society through MINT Memory Clinics, is critical to promoting greater continuity of care for people living with dementia. Strategic improvements in service integration will transform the healthcare services for people living with dementia and their families. Dr. Linda Lee, the Lead at MINT Memory Clinics, says that this can be done through "investments in accessible and collaborative team-based care, leveraging our strong infrastructure of primary care and lowering healthcare system costs."

Aging in Place

PANEL RECOMMENDATIONS:

1. Establish and expand the availibility of integrated community-based care, encompassing community support services, day programs, respite care, home care, memory clinics, occupational therapy, and medical interventions to retain the quality of life of people living with dementia.[xxvi]

2. Increase the provision of community-based care across Ontario to ensure that quality of life of people living with dementia is sustained for longer across distinct regions and socio-economic groups.[xxvii]

3. Establish local and regional based care through coordination with Ontario Health Teams (OHTs) to ensure a client-centric approach to dementia care.

4. Provide greater support to full-time employment through further compensation for professional development in dementia care.

5. Support and stabilize the 100 existing MINT clinics through their Ontario Health Teams to limit emergency room visits and hospitalizations, prolong aging at home, and delay admissions to long-term care.[xxviii]

6. Roll-out MINT memory clinics or similar dementia primary care models within Ontario Health Teams to leverage and scale throughout the province, in line with local needs and resources.[xxix]

SUMMARY OF INVESTMENTS

Support aging in place through a base funding of **$57 million** in community support services, and an additional **$150 million** funding for home care service providers.[xxx]

Continue the work done by the government in Digital First for Health Strategy with another investment of **$14 million** to expand virtual care for OHTs and home and community care providers.[xxxi]

Provide **$470 million** to increase salaries of home and community care staff.[xxxii]

Immediate Phase 1 roll-out to stabilize the existing 100 MINT clinics with an investment of **$11 million**.[xxxiii]

An investment of **$26 million** during the Phase 2 growth year establishing 15 new MINT or similar clinics in OHTs throughout the province.[xxxiv]

Annual investment of **$50 million** for the Phase 3 growth year extending further the establishment of 24 new MINT or similar clinics in OHTs throughout the province.[xxxv]

Economic Burden on People Living with Dementia and Care Partners

The National Population Health Study of Neurological Conditions estimates that by 2031, the annual healthcare costs for Canadians living with dementia will increase to $16.6 billion. For context, this is a significant increase in comparison to the $8.3 billion spent today.[xxxvi]

Overall health system and out-of-pocket expenses are 5.5 times higher for people living with dementia compared to the general population.[xxxvii]

While long-term care will always be a vital component of the province's approach to caring for those living with dementia, it need not and should not occupy the dominant position it does today: redirecting healthcare dollars into home and community options is not only the approach Ontarians want, with 80 percent of voters in 2022 in favour of moving funds towards community options. This is also the approach that will yield the best value for tax dollars. Long-term care costs average around $70,000 per individual per year, whereas prolonging home care by just half a year cuts the cost by around $26,000 per individual.[xxxviii]

Data from an evaluation sponsored by the then-Ministry of Health and Long-Term Care shows that clients receiving support from a MINT Memory Clinic had a 38 percent lower cost-per-day to the provincial healthcare system compared to other people living with dementia—and additional research shows that the MINT model saves provincial coffers around $51,000 per client.[xxxix]

With a 10:1 return on investment, an annual MINT Memory Clinic cost of $500,000 saves the healthcare system $5 million. Memory clinics, and MINT specifically, are efficient both in terms of care delivery and cost reduction.

Currently, prescription of treatment drugs is impacted by public reimbursement policies in each province. These factors play a large role in the accessibility to drugs and the quality of life of people living with dementia.

Older Ontarians often must choose between retirement homes that are privately financed and/or long-term care homes. There are not many options for seniors who are considered semi-independent. Assisted living/supportive housing options can be a more cost-effective, compassionate, and dignified option than long-term care homes for some Ontarians.

PANEL RECOMMENDATIONS:

1. Introduce fully refundable tax rebates and/or access to direct funding programs for people living with dementia and their care partners to allow them to stay in the community for longer while also reducing the strain on long-term care homes.

2. Expand access to direct funding programs to include people living with dementia and their care partners to allow them to stay in the community for longer while also reducing the strain on long-term care homes.

3. Extend the Seniors' Home Safety Tax Credit for an additional four years to encourage families to adapt homes to make them safer for people living with dementia and support aging in place.

4. Increase funding for community care to enable better access to public services for people living with dementia and reduce out-of-pocket expenses.

5. Revaluate public reimbursement policies for off-label use of pharmaceutical interventions that have high efficacy, proven safety, and demand amongst people living with dementia.

SUMMARY OF INVESTMENTS

Invest **$57 million** to expand assisted living/supporting housing to improve accessibility to 2,500 seniors.[xl]

Support for Care Partners

The role of care partners in the dementia pathway is crucial. It is critical that care partners receive the help they need, including educative, emotional, and technical support.

Care partner burnout regularly leads to premature admission to long-term care or avoidable hospitalization. As one care partner from Sault Ste. Marie told the Alzheimer Society in 2019, "a caregiver must be given care, or you will end up with two patients."

One care partner noted that they only received home care once they, themselves, experienced a stroke due to extreme stress and burnout, after which they were placed on a "crisis list". Access to supports for care partners should not require crisis in order to be accessible. Caring for care partners should be proactive, recognizing that burnout is a significant and identifiable risk especially among those caring for an individual living with dementia.

Physicians are a critical touchpoint for continuity of care, as they play an important role in providing referrals to home care support, specialist services, memory clinics, First Link® Care Navigators, day programs, respite care, and other clinical and non-clinical services.

With the limited access to services such as day programs and overnight respite, referrals can only reduce wait times but cannot improve the capacity and accessibility of these programs—this requires a greater number of resources needed to provide these services.

Another reason care partners do not reach out for these services is the prevalence of red tape. Many face the same daunting amount of paperwork to apply for respite programs as they do for permanent long-term care homes, particularly because they must often submit a new application for every program.

To add to that, these programs have limited staff resources because of frozen base funding levels. While funding remains stagnant, client capacity has increased: the same number of staff are now attempting to care for a larger volume of clients, many of whom require a greater degree of individual attention and support than in the past.

PANEL RECOMMENDATIONS:

1. Create a dedicated funding stream for dementia-specific respite services.[xli]
2. Reduce red-tape for accessing non-clinical and community support services to promote frequent use, reduce strain on care partners and retain quality of life of people living with dementia.

SUMMARY OF INVESTMENTS

Direct **15 percent** of public funding towards all respite care for dementia-specific respite services.

Elder Abuse

Elder abuse and financial abuse are far too common occurrences among people living with dementia.

Unfortunately, a discriminatory perception of seniors currently exists. A dementia diagnosis often leads to an immediate change in how someone is seen by their friends, peers, and strangers: their ability to make their own decisions is taken away from them, and they are treated as "non-persons".

It is important to note and understand that the stage of dementia influences the decision-making process. Thus, advanced-care planning is an integral component of dementia diagnosis and assessment.

Community support organizations can play an important role in providing information about financial planning, estate planning, appointing power of attorney for property and/or personal care, appointing a guardian for property or personal care, appointing a trustee for property, or providing guidance around meeting life goals and sustaining quality of life.

PANEL RECOMMENDATIONS:

1. Ensure that advanced care planning includes provision of information about financial planning, and appointing power of attorneys for property or personal care.

2. Require social workers and community support organizations to have basic knowledge to identify and respond to elder abuse within scope of practice, and to refer to appropriate resources, including legal consultants, to support people living with dementia.

3. Develop a voluntary code for dementia-friendly banking in conjunction with prominent banks and credit unions in the province.

SUMMARY OF INVESTMENTS

These are qualitative improvements.
As such, no specific financial investment is required.

Long-Term Care Homes

In 2020 the provincial government provided $5.76 billion to the long-term care sector, where the annual cost per resident summed up to $73,587. This included $12.06 per day for specialized therapies and recreational programs, and $9.54 per day for raw food materials.[xlii]

While many families are concerned with the costs associated with these homes, another big obstacle is the long waitlist. Currently, over 40,000 people are on a waitlist for one or more long-term care home(s). With the high levels of care partner burnout, people living with dementia often have little choice but to accept the first bed that becomes available, regardless of distance from their loved ones or cultural preferences.

Many families begin their application five years ahead of time to avoid crisis placement, while higher income groups secure a room at select establishments by applying 15 years in advance. Even this level of advance preparation does not guarantee a bed will be available when it is needed: CEO of AdvantAge Ontario Lisa Levin said that "most placements in the last few years have been crisis only, so [even] applying five years early is not helpful anymore."

Moreover, many people living with dementia face barriers to admission based on their cognitive ability. Some homes have used the COVID-19 pandemic as a pretense to reject applications from people living with dementia, citing concerns over the individual's ability to comply with pandemic restrictions. This practice is not legal but still prevalent.

The pandemic highlighted that many Ontarians prefer not-for-profit or municipal long-term care homes: 74 percent of Ontarians plan to select these options over private retirement homes.[xliii]

Given that 70 percent of COVID-19 cases, and 74 percent of the COVID-19 related deaths in long-term care homes across Ontario, were among residents in for-profit homes, this has deterred Ontarians from seeking admission in these homes.[xliv]

Additionally, many for-profit homes do not have dementia-specific programs and are often clustered around urban areas. Municipal homes offer more hours of care to residents and have better staff satisfaction with higher compensation.

This becomes concerning given that 57 percent of long-term care homes in Ontario are owned by private for-profit organizations while only 16 percent are publicly owned.[xlv] It is important to rethink how Ontario can leverage existing long-term care capacity to ensure quality care for people living with dementia.

While governments across the country are focused on increasing long-term care capacity, Ontario's current focus on building more beds is only one part of the solution; it must be complemented with other funding and policy changes. A panelist recommends building smaller long-term care homes that are strategically scattered across the province to improve the accessibility to people living with dementia.

Additionally, there is insufficient attention being given to other key aspects of infrastructure, including Wi-Fi for residents, plugs or outlets in each room, automated doors or windows in facilities, and universal design in these homes. It is important to note that consumer technology can be integrated into long-term care homes: it is not always necessary to focus on medical technology.

Many long-term care homes do not operate with a philosophy that centres around the individual. This is often because our long-term care sector is under-funded and highly regulated, with the staff often spending more time drafting reports than providing care to residents. Moreover, with two-thirds of long-term care residents in Ontario living with dementia, there is a need to adopt a model that prioritizes dementia care.

Mental health care needs to be provided in the home. Residents need access to psychiatric and medical assessments, which is why the availability of psychiatrists, nurses, and multidisciplinary teams is important.[xlvi] Two to three interactions per week between residents and care partners are important so that their moods and behaviours are monitored, and deterioration does not go undetected and unaddressed.[xlvii]

Violence or responsive behaviours are common occurrences in long-term care homes, and part of the challenge is under-stimulation and lack of training provided to care providers. Long-term care homes need to adopt emotion-focused models of care such as the Butterfly Model of Care, The Eden Alternative®, or The Green House Project. These programs offer social contact and addresses individual needs, preventing rapid deterioration. Moreover, integrating long-term care homes into the community and vice versa can break down the current "us versus them" mindset.

One of the most effective and welcomed ways to reduce the strain on the long-term care sector is by incentivizing and supporting individuals in their desire to remain in the community for longer.

In Ontario, the province includes home care visits in its publicly funded healthcare services. Despite this, there is a clear mismatch between Ontarians with dementia who live at home, and Ontarians with dementia who want to live at home: 95 percent of Ontario residents have expressed a desire to age at home for as long as possible, while only 60 percent of Ontarians with dementia live at home.

Moreover, today, eight percent of residents entering long-term care homes in Ontario could have continued to be cared for at home if they had access to a robust suite of home and community care services: they do not need a bed in long-term care, but it was the only option available to them due to limited support for home care.[xlviii]

PANEL RECOMMENDATIONS:

1. Implement an emotion-focused model of dementia care that encourages long-term care staff to look at the increased quality of life of dementia clients as the main indicator of their practice.

2. Conduct routine monitoring and evaluations to ensure that long-term care homes operate on a person-centric philosophy so that care and services provided are unique to individual needs.

3. Place transitional support in long-term care homes to assist new long-term care home residents and their care partners upon admission.

4. Reduce red tape for planning and admission into long-term care homes by ensuring that home care workers, social workers, and care navigators follow up routinely with people living with dementia and their care partners and provide referrals accordingly.

5. Complement the current plan of expanding long-term care homes and building long-term care beds by ensuring that the sector has sufficient health human resource capacity and well-trained staff to provide adequate care for older Ontarians, particularly dementia care and behavioural support.

6. Ensure that investments towards long-term care homes facilitate the adoption of dementia-specific programs and well-trained staff to care for residents living with dementia.

7. Establish mental health care programs in long-term care homes by placing psychiatrists, nurses, and multidisciplinary teams for routine assessment of residents and care partners who need the support.

8. Mandate the inclusion and availability of dementia care programs that maintain quality standards in all long-term care homes to ensure equitable access across the province.

9. Establish dispute resolution mechanisms in long-term care homes between administration and care partners of people living with dementia.

SUMMARY OF INVESTMENTS

Maintain and execute the **$246 million** investment from Budget 2021 to improve residents' quality of life by upgrading long-term care homes with a key focus on universal design.

Ensure that the government's commitment of nearly **$4 billion** to connect all regions in the province to high-speed internet also expands to every resident of long-term care.

Execute the **$4.9 billion** commitment over the next four years to hire 27,000 long-term care home staff.[xlix]

An investment of **$4 million** directed towards Alzheimer Society's U-First!® education program will ensure that long-term care homes are better equipped to care for patients living with dementia.[l]

Stigma Associated with Dementia

Ageism and the stigma associated with dementia are key barriers in providing better dementia care. Stigma hinders public and physician willingness to seek and provide a diagnosis: there is often a shared belief that nothing can be done, so why bother—or worse, that a diagnosis will actually do more harm than good.

Many people are so terrified of dementia and "losing their personality" that they will not go in for an assessment. But addressing this fear could help with early detection and diagnosis of dementia.

Socioeconomic differences lead to different dementia diagnoses. Within some communities in particular, dementia is underdiagnosed compared to others. Culturally specific activities are necessary to find the care and support needed with the language and cultural references that are compatible to these individuals.

Moreover, once someone gets dementia, they tend to purposefully restrict themselves. There is need for further education for people living with dementia and their care partners to know what to expect and when to make decisions.

Additionally, provision of long-term care and dementia care is still seen with the stigma of charity, such that people should "just be happy" with what they are given.

PANEL RECOMMENDATIONS:

1. Create a province-wide dementia awareness campaign, to preserve individual rights of people living with dementia and their care partners and expand community support to sustain quality of life.

SUMMARY OF INVESTMENTS

Invest **$5 million** in 10 provincial projects across the province to raise awareness of dementia to complement the national dementia strategy.[li]

Preventing Dementia

Many Ontarians believe that dementia is definitive and cannot be prevented. Yet, up to 40 percent of dementia cases can be prevented in people by controlling diet, regular physical activity, and engaging in more social activities. [lii]

It is important to start before diagnosis and look closely at risk reduction options: avoiding concussions, preventing mid-life hypertension risk factors, and treating hearing impairment are some preventative steps that can be taken long before symptoms emerge.

Moreover, reducing strokes can also help prevent dementia. Often strokes can double the chances of dementia and thus, over one-third of dementia cases can be avoided by preventing strokes.[liii] Forty-five percent of stroke patients who do not live with dementia can be sent back home from hospital without additional support but only 14 percent of people living with dementia who experience a stroke can do the same.[liv]

With an aging population and longer life spans, the number of strokes will increase and so will the likelihood of developing dementia. Routinely monitoring blood pressure, cholesterol, and other risk factors is important in forming a management plan.

We also need to note the differences between natural aging and mild cognitive impairment. A person who is diagnosed with dementia often experiences mild cognitive impairment 10 years prior.

PANEL RECOMMENDATIONS:

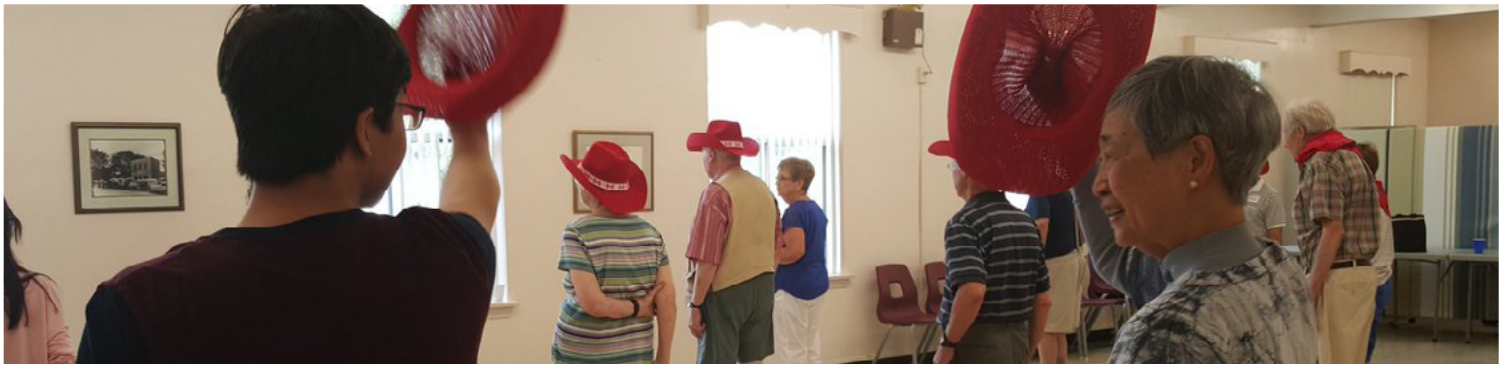
1. Inclusion of the promotion of good lifestyle habits such as healthy diets and frequent exercise in the best practices of primary care to prevent cognitive impairment and dementia.

2. Inclusion of prevention plans for strokes in the best practices of primary care to reduce the risk of developing dementia.

3. Emphasize the importance of management plans for diabetes, cholesterol, high blood pressure, and other conditions that pose a risk for the development of dementia.

SUMMARY OF INVESTMENTS

These are qualitative improvements.
As such, no specific financial investment is required.



Policy Assessment

This report has highlighted the unintended yet existing policy mismatch between the government's priorities and the needs of dementia care sector.

Collectively and as partners, Ontario must focus on building a healthcare system that is proactive versus reactive. Greater cooperation is needed among policy makers, clinicians, specialists, and dementia care partners and care providers during the planning of a renewed dementia strategy. This is required to shift the focus towards the quality of life of people living with dementia and their care partners. It will also help those living with dementia remain in their homes longer and offer a greater sense of dignity and compassion.

While the Ontario Health Team model has shown some initial success in bringing clients and providers together to advance shared care priorities, much of the work to improve dementia care is regionalized and hospital led. There is a need for a pan-Ontario body with the authority to examine problems related to dementia care, monitoring efficacy of current investments and making recommendations for further policy priorities.

Regional leadership can help test and scale new models of care, implement standards, and collect data to inform a renewed Ontario Dementia Strategy. Local Alzheimer Societies and other care providers have an important role in supporting OHTs with dementia-specific resources.

PANEL RECOMMENDATIONS:

1. Draft and implement a renewed Ontario Dementia Strategy under the purview of a dedicated Secretariat, with the authority to oversee dementia care and make recommendations across the spectrum of government services, including health and long-term care.

2. Develop and launch multi-year interventions with a robust evaluation framework to improve dementia care capacity and retention of support staff.

3. Ensure people living with dementia, physicians, specialists, social workers, and other core staff are part of the discussion while developing and introducing new dementia care programs.

SUMMARY OF INVESTMENTS

These are qualitative improvements.
As such, no specific financial investment is required.



Timely Action

Our panel proposes an achievable timeframe for the adoption of this strategy over the next four years. Working with government, we recommend an initial focus on policy tweaks and items that do not require heavy investment.

The subsequent actions should prioritize investments to support aging in place and long-term care homes by incorporating these recommendations into Budget 2023.

PHASE ONE

- Publicly commit to a renewed Ontario Dementia Strategy.
- Appoint a Secretariat to oversee dementia care and involve different Ministries within government to address current challenges.
- Improve educational infrastructure by changing the curriculum and provide further investments for training physicians and personal support workers (PSWs).
- Change the compensation model for healthcare professionals, PSWs, and social workers to prevent staff turnover and incentivize more individuals to practice dementia care.
- Adopt and mandate Health Quality Ontario (HQO) standards for dementia care to promote a clear dementia pathway.
- Establish funding streams for educational programs provided by community organizations.
- Roll out investments to support the existing 100 MINT Memory Clinics.
- Maintain relationships with stakeholders throughout all phases to ensure the effectiveness of the dementia strategy.

PHASE TWO

- Improve diagnostic capacity through key investments and adapting the existing best practices for diagnosis and assessment.
- Initiate discussions on preventative measures and promote dementia-friendly communities through a province-wide awareness campaign.
- Reduce red tape for accessing non-clinical and community support services.
- Mandate the inclusion of dementia-care programs in long-term care homes.
- Ensure that social workers and community support organizations have basic knowledge to discuss advanced care planning and identify and respond to elder abuse.
- Direct investment towards home care service providers.
- Direct investments to establish 15 new MINT or similar clinics in OHTs throughout the province.

PHASE THREE

- Establish a dementia-specific funding stream for respite programs.
- Invest in IT infrastructure, including hardware and software, to make community support services and non-clinical services more accessible to people living with dementia.
- Direct a portion of funds for improving internet connectivity within the province towards long-term care homes.
- Support the expansion of community support services and non-clinical services to rural Ontario.
- Implement tax rebates and other reimbursement models for people living with dementia and their care partners.
- Maintain annual investments to support MINT Memory Clinics.

PHASE FOUR

- Review public reimbursement policies for off-label use of pharmaceutical interventions.
- Invest in assisted living/ supporting housing for seniors.
- Upgrade long-term care homes to preserve the quality of life of residents.
- Revisit the existing compensation model for healthcare professionals, personal support workers, and social workers and make corrections based on the demand for the services and existing inflation rate.

PHASE FIVE

- Conduct a review of all these policy actions and initiate a consultation with stakeholders to map out a plan to address the lingering gaps within dementia care.
- Incorporate results and learnings into a further iteration of Ontario's Dementia Strategy, to build on progress achieved.

Conclusion

The past two pandemic years have been difficult for everyone. This is especially true for older Ontarians who struggled with access to care and experienced isolation.

As the province continue to move beyond the pandemic, the hope is that this strategy encourages enhanced empathetic consideration of our older populations. This **Roadmap Towards a Renewed Ontario Dementia Strategy** highlights a real and growing concern in dementia care. It is not too late to adapt for current and future generations—and to avoid healthcare system capacity and financial overload, the provincial government must consider these three findings for dementia care in Ontario:

Draft and implement a renewed Ontario Dementia Strategy under the purview of a dedicated Secretariat, with the authority to oversee dementia care and make recommendations across the spectrum of government services, including health and long-term care.

Establish integrated community-based care encompassing community support services, day programs, respite care, home care, memory clinics, occupational therapy, and medical interventions to retain the quality of life of people living with dementia.

Complement the current plan of expanding long-term care homes and building of new long-term care beds by ensuring that the sector has sufficient health human resource capacity and well-trained staff to provide adequate care for older Ontarians, particularly dementia care and behavioural support.

Endnotes

[i] "Developing Ontario's Dementia Strategy: Discussion Paper". https://www.ontario.ca/page/developing-ontarios-dementia-strategy-discussion-paper.
[ii] *7 Reasons to Care.* 2022. https://irp.cdn-website.com/9100a73e/files/uploaded/OCSA-PreBudgetReport2022-web.pdf.
[iii] *Caregiver Support Framework*. https://alzheimer.ca/york/sites/york/files/documents/caregiver_support_framework_may_2018.pdf.
[iv] Christina Stergiou-Dayment, Interviewed by Dr. Alexander Santelli, Ph.D, Virtual, 2022.
[v] Christina Stergiou-Dayment, Interviewed by Dr. Alexander Santelli, Ph.D, Virtual, 2022.
[vi] Christina Stergiou-Dayment, Interviewed by Dr. Alexander Santelli, Ph.D, Virtual, 2022.
[vii] Health Quality Ontario. "Dementia: Care for People Living in The Community".
[viii] Health Quality Ontario. "Dementia: Care for People Living in The Community".
[ix] Health Quality Ontario. "Dementia: Care for People Living in The Community".
[x] Christina Stergiou-Dayment, Interviewed by Dr. Alexander Santelli, Ph.D, Virtual, 2022.
[xi] Christina Stergiou-Dayment, Interviewed by Dr. Alexander Santelli, Ph.D, Virtual, 2022.
[xii] *The Value of Continuity— Investment in Primary Care Saves Costs and Improves Lives.* https://www.cfpc.ca/CFPC/media/Resources/Health-Care-Delivery/Continuity-of-Care-one-pager-ENG-Final.pdf.
[xiii] Mondor, Luke, Colleen J. Maxwell, David B. Hogan, Susan E. Bronskill, Andrea Gruneir, Natasha E. Lane, and Walter P. Wodchis. 2017. "Multimorbidity And Healthcare Utilization Among Home Care Clients With Dementia In Ontario, Canada: A Retrospective Analysis Of A Population-Based Cohort". *PLOS Medicine* 14 (3): e1002249. doi:10.1371/journal.pmed.1002249.
[xiv] Christina Stergiou-Dayment, Interviewed by Dr. Alexander Santelli, Ph.D, Virtual, 2022.
[xv] "Ontario Invests in Permanent PET Scanner in Sudbury". https://news.ontario.ca/en/release/35333/ontario-invests-in-permanent-pet-scanner-in-sudbury.
[xvi] *A Dementia Care System For All Ontarians.* 2022. https://alzheimer.ca/on/sites/on/files/documents/Pre-Budget%20Submission%202022_EN.pdf.
[xvii] Basu, Monisha, Tracy Cooper, Kelly Kay, David B. Hogan, José A. Morais, Frank Molnar, Robert E. Lam, and Michael J. Borrie. 2021. "Updated Inventory and Projected Requirements for Specialist Physicians in Geriatrics". *Canadian Geriatrics Journal* 24 (3): 200-208. doi:10.5770/cgj.24.538.
[xviii] Basu, Monisha, Tracy Cooper, Kelly Kay, David B. Hogan, José A. Morais, Frank Molnar, Robert E. Lam, and Michael J. Borrie. 2021. "Updated Inventory and Projected Requirements for Specialist Physicians in Geriatrics". *Canadian Geriatrics Journal* 24 (3): 200-208. doi:10.5770/cgj.24.538.
[xix] "Ontario Boosting Access to Primary Care for People Across the Province". https://news.ontario.ca/en/release/44674/ontario-boosting-access-to-primary-care-for-people-across-the-province.
[xx] *The Value of Continuity— Investment in Primary Care Saves Costs and Improves Lives.* https://www.cfpc.ca/CFPC/media/Resources/Health-Care-Delivery/Continuity-of-Care-one-pager-ENG-Final.pdf.
[xxi] Health Quality Ontario. "Dementia: Care for People Living in The Community".
[xxii] "Unpaid Caregiver Challenges And Supports | CIHI". https://www.cihi.ca/en/dementia-in-canada/unpaid-caregiver-challenges-and-supports#admission.
[xxiii] Staffing Crisis Threatens Home And Community Care Sector With 421% Increase In Vacant RN Positions And 331% Increase In Vacant PSW Positions". https://www.ocsa.on.ca/staffing-crisis-threatens-home-and-community-care-sector-with-421-increase-in-vacant-rn-positions-and-331-increase-in-vacant-psw-positions#:~:text=This%20means%20PSWs%20in%20the,working%20in%20long%2Dterm%20care.
[xxiv] *7 Reasons to Care.* 2022. https://irp.cdn-website.com/9100a73e/files/uploaded/OCSA-PreBudgetReport2022-web.pdf.
[xxv] MINT Memory Clinic. 2021. "Delivering Faster, Integrated Dementia Care In Ontario".
[xxvi] Christina Stergiou-Dayment, Interviewed by Dr. Alexander Santelli, Ph.D, Virtual, 2022.
[xxvii] Christina Stergiou-Dayment, Interviewed by Dr. Alexander Santelli, Ph.D, Virtual, 2022.
[xxviii] Dr. Linda Lee, Interviewed by Dr. Alexander Santelli, Ph.D, Virtual, 2022.
[xxix] Dr. Linda Lee, Interviewed by Dr. Alexander Santelli, Ph.D, Virtual, 2022.
[xxx] *7 Reasons to Care.* 2022. https://irp.cdn-website.com/9100a73e/files/uploaded/OCSA-PreBudgetReport2022-web.pdf
[xxxi] "Ontario Expanding Innovative Home and Community Care Services" https://news.ontario.ca/en/release/59437/ontario-expanding-innovative-home-and-community-care-services.
[xxxii] *7 Reasons to Care. 2022.* https://irp.cdn-website.com/9100a73e/files/uploaded/OCSA-PreBudgetReport2022-web.pdf.
[xxxiii] Dr. Linda Lee, Interviewed by Dr. Alexander Santelli, Ph.D, Virtual, 2022.
[xxxiv] Dr. Linda Lee, Interviewed by Dr. Alexander Santelli, Ph.D, Virtual, 2022.
[xxxv] Dr. Linda Lee, Interviewed by Dr. Alexander Santelli, Ph.D, Virtual, 2022.
[xxxvi] "How Dementia Impacts Canadians" https://www.cihi.ca/en/dementia-in-canada/how-dementia-impacts-canadians.
[xxxvii] "How Dementia Impacts Canadians". https://www.cihi.ca/en/dementia-in-canada/how-dementia-impacts-canadians.
[xxxviii] MINT Memory Clinic. 2021. "Delivering Faster, Integrated Dementia Care In Ontario".
[xxxix] Dr. Linda Lee, Interviewed by Dr. Alexander Santelli, Ph.D, Virtual, 2022.
[xl] AdvantAge Ontario. 2022. "Fulfilling the Pledge: Transforming Seniors' Care"
[xli] *A Dementia Care System For All Ontarians.* https://alzheimer.ca/on/sites/on/files/documents/Pre-Budget%20Submission%202022_EN.pdf.
[xlii] "Facts And Figures". https://www.oltca.com/oltca/OLTCA/Public/LongTermCare/FactsFigures.aspx.
[xliii] New Poll Finds Significant Support For More Not-For-Profit Long-Term Care Beds In Ontario". https://www.cp24.com/news/new-poll-finds-significant-support-for-more-not-for-profit-long-term-care-beds-in-ontario-1.5704294.
[xliv] Levin, Lisa. "Covid-19 And Long-Term Care: Tale of Two Pandemics". Presentation, 2020.
[xlv] "Long-Term Care Homes In Canada: How Many And Who Owns Them? | CIHI". https://www.cihi.ca/en/long-term-care-homes-in-canada-how-many-and-who-owns-them.
[xlvi] Checkland, Claire, Sophiya Benjamin, Marie-Andrée Bruneau, Antonia Cappella, Beverley Cassidy, David Conn, and Cindy Grief et al. 2021. "View Of Position Statement For Mental Health Care In Long-Term Care During COVID-19 | Canadian Geriatrics Journal". *Cgjonline.Ca.* https://cgjonline.ca/index.php/cgj/article/view/514/748.
[xlvii] Checkland, Claire, Sophiya Benjamin, Marie-Andrée Bruneau, Antonia Cappella, Beverley Cassidy, David Conn, and Cindy Grief et al. 2021. "View Of Position Statement For Mental Health Care In Long-Term Care During COVID-19 | Canadian Geriatrics Journal". *Cgjonline.Ca.* https://cgjonline.ca/index.php/cgj/article/view/514/748.
[xlviii] "How Dementia Impacts Canadians". https://www.cihi.ca/en/dementia-in-canada/how-dementia-impacts-canadians.
[xlix] "Ontario Taking Action to Further Increase Staffing in Long-Term Care, Leading to More Direct Care for Residents". https://news.ontario.ca/en/release/1001774/ontario-taking-action-to-further-increase-staffing-in-long-term-care-leading-to-more-direct-care-for-residents.
[l] "Advocacy Efforts in Ontario". https://alzheimer.ca/on/en/take-action/change-minds/advocacy-efforts-ontario.
[li] "Government Of Canada Invests in Projects That Raise Awareness of Dementia and Promote Dementia-Inclusive Communities". https://www.canada.ca/en/public-health/news/2022/01/government-of-canada-invests-in-projects-that-raise-awareness-of-dementia-and-promote-dementia-inclusive-communities.html.
[lii] Seitz, Dallas. "Assessment, Diagnosis and Management of Dementia". Presentation, 2021.
[liii] Hachinski, Vladimir, Karl Einhäupl, Detlev Ganten, Suvarna Alladi, Carol Brayne, Blossom C.M. Stephan, and Melanie D. Sweeney et al. 2019. "Preventing Dementia By Preventing Stroke: The Berlin Manifesto". Alzheimer's & Dementia 15 (7): 961-984. doi:10.1016/j.jalz.2019.06.001.
[liv] Mind The Connection: Preventing Stroke And Dementia. https://www.heartandstroke.ca/-/media/pdf-files/canada/stroke-report/hsf-stroke-report-2016.ashx?la=en&hash=B84FFD2C434B4E3F5CF4585D9CB35713E6C406E5.

In Ontario, dementia is hallway healthcare.
Dementia is long-term care.
We can do better.

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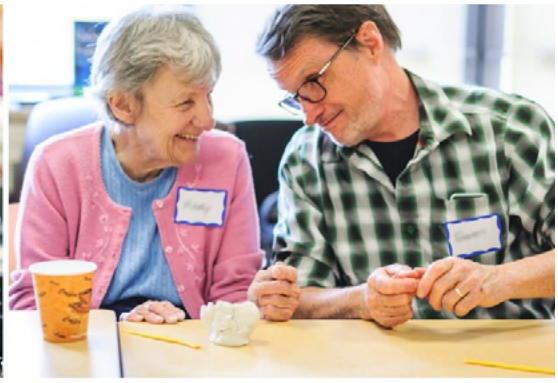

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