

A Dementia

**Alzheimer** *Society*  
ONTARIO



# **A Dementia Care System for All Ontarians**

**2022 Pre-Budget Submission**  
*from the Alzheimer Society of Ontario*

# Building a dementia care system that supports those who work in it, and those who rely on it.

## Summary of Recommendations

1. Commit to a home-and community-centric system of care for Ontarians living with dementia.
2. Create a dedicated funding stream for dementia-specific respite services.
3. Support more Ontarians living with dementia, their care partners, and families with an investment of \$3.26 million in First Link® System Navigation.
4. Explore innovative staffing models to divert people living with dementia away from hospital emergency departments.
5. Reduce unnecessary hospital visits by funding transitional community supports for people living with dementia moving to a long-term care home.
6. Mandate a minimum standard of dementia-specific knowledge and skills to give long-term care home staff the tools they need to care with compassion.
7. Respond to the number one need expressed by care partners and implement a new, refundable provincial Primary Caregiver Tax Credit.
8. Remove barriers to self-directed care funding by expanding program eligibility to include people living with dementia and their care partners and/or power of attorney.

## About the Alzheimer Society

The Alzheimer Society is a federation of 27 community support providers operating in every corner of Ontario. We supported over 100,000 clients last year, including both care partners and people living with dementia. We provide education and training to physicians and other health care professionals, as well as the general public. With hundreds of staff and thousands of volunteers, we seek to alleviate the personal and social consequences of Alzheimer's disease and other dementias, and promote research into a cure and disease-altering treatment.

## Building a Dementia Care System That Works—For Everyone

*Dementia will be among the defining societal challenges of the coming decades. An ageing population that is living longer means health and long-term care systems already struggling to cope with the quarter million Ontarians living with dementia today will be called upon to support twice as many within the next 20 years.*

Dementia is an umbrella term for a set of symptoms caused by disorders of the brain. The most common form of dementia in Ontario and around the world is Alzheimer's disease. While there is no cure, some types of dementia can be treated and there are steps everyone can take to reduce their risk. For the majority of those diagnosed, however, the disease causing their dementia will eventually be fatal.

The COVID-19 pandemic has exposed tragic but longstanding flaws in how Ontario cares for those living with dementia. Insufficient home and community care capacity is forcing individuals living with dementia to turn to hospitals and long-term care homes not because they need that level of care, but because they have nowhere else to turn. With proper support, 8% of current long-term care residents in Ontario could be living at home<sup>1</sup>—representing a staggering 8,000 unnecessarily occupied beds, and over 3,000 individuals on waiting lists for long-term care who could continue living where they want to be: at home.

Failing to properly support Ontarians living with dementia in their desire to age at home has directly led to the capacity constraints in our hospital and long-term care systems that have been so tragically highlighted over the past two years. Efficient, compassionate care demands that those living with dementia be supported to receive care in a place of their choosing. For some, this will be a long-term care home—and residents living with dementia deserve to be cared for by staff with a fulsome understanding of dementia as a disease and how it impacts behaviour, so they can deliver care in a way that respects every resident's right to independence and individuality. For the 150,000 Ontarians with dementia who live at home, they deserve access to a comprehensive suite of home and community care options that can support their evolving care needs.

Over a quarter of a million Ontarians live with dementia today, a number that is expected to double within the next twenty years. The Alzheimer Society has eight recommendations to better support those living with dementia and their care partners today, and prepare for the growing number who will be affected in years and decades to come.

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<sup>1</sup> National Institute on Ageing. *Bringing Long-Term Care Home*, November 2020.

## Right Care, Right Time, Right Place

### Let's keep Ontarians living with dementia where they want to be: at home.

Hallway health care is dementia. Long-term care is dementia. Capacity constraints in both settings, highlighted by the COVID-19 pandemic but present long before it, can be traced directly to over-stretched and under-funded community supports that force Ontarians living with dementia to move to a long-term care home before they need to, or to make an avoidable trip to their local hospital when they shouldn't have to.

Across Canada, half of all alternate level of care (ALC) days are attributed to older adults living with dementia. With over 5,000 ALC patients across Ontario on a usual day<sup>2</sup>, each costing the province \$730 per day, providing a quality community alternative for people living with dementia is a cost-effective, compassionate way to alleviate pressure on our hospitals.

The same is true in long-term care homes, where about two-thirds of residents live with dementia and 90% have some form of cognitive impairment. Consistently and overwhelmingly, older adults in Ontario express their desire to age at home. This desire aligns with what is best for Ontario's health and long-term care systems, not to mention communities and neighbourhoods themselves where older adults are vibrant and active members. Around 8% of residents in Ontario's long-term care homes do not need to be there: with intensive community supports, they could be cared for at home, where they want to be and at roughly half the cost to taxpayers.

The home and community care sector, including local Alzheimer Societies, is nimble, efficient, cost-effective—and ready to do more. Home and community care is the lynchpin to freeing up hospital and long-term care capacity. The Alzheimer Society has four recommendations to unleash the sector's potential:

#### **Commit to a home- and community-centric system of care for Ontarians living with dementia.**

The Alzheimer Society supports a recommendation from the Ontario Community Support Association (OCSA) to increase funding for the home and community care sector by \$586 million, as well as all other recommendations contained in their 2022 pre-budget submission. We call on the Government of Ontario to commit the necessary resources to ensure all Ontarians living with dementia have the option to age at home as long as their condition allows, and as long as that is their choice.

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<sup>2</sup> Ontario Community Support Association. *Home and Community Care: Cost-Effective and Crucial for an Aging Population*, October 2020.

**Create a dedicated funding stream for dementia-specific respite services.**

The second report from the Premier's Council on Improving Healthcare and Ending Hallway Medicine found that: "For family caregivers supporting patients with dementia, extended hours for respite or additional access to support overnight would help make it possible to keep their family member at home longer rather than moving them to a long-term care home". We call on the provincial government to act on this recommendation and establish a dedicated funding stream to expand access to dementia-specific respite services, including overnight options where appropriate.

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

The First Link® program is a lifeline to families affected by dementia, and a conduit to services and supports available in their community. Prompt referral to First Link® has been shown to delay admission to long-term care, avoid unnecessary hospital visits, and increase the ability of both people living with dementia and care partners to live safely at home. Yet this vital program is stretched well past its capacity: a funding increase planned for 2020 did not materialise, leading to wait times of up to seven months across the province. We call on the Government of Ontario to fully fund First Link® System Navigation with an additional investment of \$3.26 million, which will be put to use immediately: the Alzheimer Society is ready and able to hire staff and begin serving more clients on day one of this new investment.

**Explore innovative staffing models to divert people living with dementia away from hospital emergency departments.**

Older Canadians living with dementia are 65% more likely to be hospitalised, spend 2.5 hours longer in the emergency room, and are at higher risk of harm while in hospital compared to the general older adult population<sup>3</sup>. Far too often a trip to hospital for someone living with dementia offers only a temporary solution to a recurring problem. Instead, every hospital visit should be seen as an opportunity to break the cycle of home-to-hospital and connect Ontarians living with dementia with the community supports they need to live safely at home. Encouraging pilot project data from the Hamilton area suggests that embedding staff with specialised knowledge of dementia and local home and community care supports in hospital emergency rooms can help avoid an admission, and reduce subsequent hospital visits. We call on the provincial government to explore this model and others, to leverage the home and community care sector and reduce unnecessary hospital visits among Ontarians living with dementia.

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<sup>3</sup> Canadian Institute for Health Information. *Dementia in Canada*, June 2018.

## Long-Term Solutions

### Equip health care heroes with the tools they need to care with compassion.

In Ontario, dementia is long-term care. Over two-thirds of long-term care residents live with dementia, and a full 90% have some form of cognitive impairment. Supporting Ontarians with dementia in their desire to live at home is a big part of solving long-term care, but this is not an option for everyone. Our long-term care system must be ready to meet the individual needs of every resident with compassion and understanding. Despite the best efforts of thousands of selfless health care heroes, that is not the reality today.

Residents with complex care needs can travel endlessly through the revolving door between hospital and long-term care. For residents living with dementia, the risk of unnecessary hospitalisation is particularly high immediately following admission. A move to long-term care is a traumatic experience for someone living with dementia: adapting to a radically different environment, with unfamiliar faces and routines, often in a space with excessive noise and other sensory stimulation. A trusted companion can help guide residents through these overwhelming first weeks.

This person-centred approach must continue for the entire duration of a resident's time at a given home. The bare minimum is not good enough: we regularly hear heartbreaking stories of residents living with dementia being neglected because their ways of communicating are not understood, their forms of expression mistaken for non-compliance. Dementia changes how a person reacts in everyday situations, how they make their needs known. For example a resident living with dementia might refuse to eat if another need is unmet—such as if they are experiencing unaddressed pain, or if their room is too hot or cold. A staff member not familiar with how dementia impacts behaviour might write this off as the resident being “difficult” and report that they have refused food.

The Alzheimer Society fully supports calls to action contained in the pre-budget submission of the Ontario Seniors Care and Assistance Roundtable (OSCAR), and highlights two specific recommendations to build a long-term care system that works for people living with dementia:

#### **Reduce unnecessary hospital visits by funding transitional community supports for people living with dementia moving to a long-term care home.**

A move to long-term care is stressful and traumatic, especially for someone living with dementia. Transitioning to a new environment with unfamiliar schedules, routines, and faces causes confusion, and can result in responsive behaviours and deterioration in the resident's physical and cognitive wellbeing. Time-limited support from a trusted community partner can help make this transition easier. A pilot project supported by Ontario Health North has shown great success: by enabling an Alzheimer Society staff member to

support someone living with dementia for up to two weeks as they settle in to their new home, hospital visits have been reduced and some long-term care homes in Northern Ontario now insist on Alzheimer Society involvement as a precondition for accepting an application. And staff trained by Behavioural Supports Ontario (BSO) embedded within long-term care homes continue to offer on-the-job support and informed, customised strategies to their colleagues on how to compassionately care for those living with dementia and other conditions resulting in changed behaviour—but BSO staff are not available in all homes, and often have other duties that limit their ability to provide behavioural support. We encourage the Government of Ontario to investigate and fund these and other proven models of providing activation and behavioural support for long-term care residents.

**Mandate a minimum standard of dementia-specific knowledge and skills to give long-term care home staff the tools they need to care with compassion.**

Dementia must be the rule, not the exception, when training long-term care home staff and management. Two-thirds of all residents live with dementia: their unique needs must be understood by everyone working in a long-term care home. The new regulatory Authority established under Bill 283 presents an opportunity to mandate a minimum level of dementia-specific knowledge for all personal support workers across Ontario. Likewise Bill 37 gives the Ministry of Long-Term Care the authority to mandate training for home leaders on a number of topics, including dementia. We call on the provincial government to use its regulatory power to ensure everyone—including management, frontline, and support staff—working in a long-term care home has a comprehensive understanding of dementia, how it impacts behaviour, and how to deliver person-centred care to people of all cognitive abilities.

## Caring for Care Partners

### Support those who support our most vulnerable friends and neighbours.

Care partners are the unsung heroes of our health care system. Asking nothing in return, they sacrifice their own physical, mental, and financial wellbeing to support a family member or friend. Care partners often report greater levels of stress and anxiety compared to the general population, and four in ten have to step back from their careers due to their caregiving role<sup>4</sup>.

Being a care partner for someone living with dementia adds an additional level of complexity to an already challenging role. Care partners for an older adult living with dementia devote 50% more time to caregiving and are 73% more likely to experience distress compared to the general care partner population<sup>5</sup>. Without proper supports to manage the physical, emotional, and financial toll of caregiving, care partners can end up becoming patients themselves.

A health care system without care partners would be a system in danger of collapse. The overwhelming majority—70%—of home care in Ontario is provided by care partners, with nearly 850,000 Ontarians providing more than ten hours of care per week<sup>6</sup>. Across Canada care partners save health care systems an estimated \$25 billion—not including \$1.4 billion of their own money in out-of-pocket expenses every year<sup>7</sup>.

Instead of the respect and support they deserve, care partners report feeling consistently drained and in desperate need of respite. In collaboration with the Ontario Caregiver Coalition, we have two recommendations to improve the quality of life of care partners across Ontario:

#### **Respond to the number one need expressed by care partners and implement a new, refundable provincial Primary Caregiver Tax Credit.**

Over two-thirds of care partners across Canada report being in need of financial support, but less than a quarter receive any. A 2020 survey by the Ontario Caregiver Coalition found that financial distress continues to be the single biggest issue facing care partners in Ontario—and it's getting worse: the Ontario Caregiver Organization reports that nearly half of care partners experienced financial hardship in 2021, more than double the number recorded in 2018<sup>8</sup>. The only dedicated government assistance available to all care partners is the Canada Caregiver Credit which gives, at most, under \$10,000 in non-refundable

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<sup>4</sup> Statistics Canada. *Portrait of Caregivers*, September 2013.

<sup>5</sup> CIHI, 2018.

<sup>6</sup> Expert Group on Home & Community Care. *Bringing Care Home*, March 2015.

<sup>7</sup> CIHI, 2018 and National Institute on Ageing, *Why Canada Needs to Better Care for its Working Caregivers*, March 2018.

<sup>8</sup> Ontario Caregiver Organization. *Spotlight Report, The Impact of Covid-19 on Caregivers: Year Two*, November 2021.

credits, meaning those care partners who are retired or had to step back from their career due to their caregiving role—those in the greatest need—often receive nothing at all.

The federal government has promised action, with a commitment in ministerial mandate letters to convert the current Canada Caregiver Credit into a fully refundable tax-free benefit. This is an opportunity for Ontario to take national leadership by instituting a new, fully refundable Primary Caregiver Tax Credit that meets or exceeds the standard set by Manitoba. We call on the Government of Ontario to set an example for the rest of the country to follow.

**Remove barriers to self-directed care funding by expanding program eligibility to include people living with dementia and their care partners and/or power of attorney.**

Of the quarter million Ontarians who live with dementia today, 60%—or around 150,000—live in the community. The overwhelming majority of older adults, including those living with dementia, want to age at home, and supporting this desire is in the best interests of the health care system. Yet one avenue of accessing in-home supports—self-directed care—is not accessible to Ontarians living with dementia, unlike most other provinces where such programs are offered. This leaves those without the financial means to pay for private in-home support with few options other than a premature move to long-term care. We encourage the provincial government to expand eligibility criteria for self-directed and family-managed home care programs to include people living with dementia as well as their care partners and/or power of attorney. Further, we express our full support for the five recommendations related to self-directed care made by the Ontario Caregiver Coalition in their pre-budget submission.

## Building a Resilient, Compassionate Dementia Care System

**Acting today to improve the quality of life and care for Ontarians living with dementia and their care partners, wherever they live, will free up health and long-term care capacity today while helping to build a better system for tomorrow.**

Health and long-term care systems in Ontario do not serve people living with dementia efficiently. This was true long before COVID-19.

A story we hear far too often follows similar lines as this: a client waits for four, five, six months or longer to access in-home respite support. During this wait period, a crisis situation develops and the person living with dementia is admitted to hospital. Unable to safely return home, the person remains in hospital as an ALC patient and is placed on yet another waiting list, this time for a long-term care bed. After three weeks in hospital, occupying a bed they neither need nor want, the client is moved to LTC where their condition deteriorates further due to a confusing, unfamiliar environment. All this because they were unable to access an extra hour or two of home and community supports per week.

We invite the Government of Ontario to use Budget 2022 as an opportunity to break this cycle. The home and community care system is lean, efficient, and ready to do more. Care partners are already doing more than their fair share, but are not getting the help they so desperately need.

The Alzheimer Society of Ontario is eager to contribute to building a health and long-term care system that cares for people living with dementia more efficiently and compassionately. Together, we can build a dementia care system for all Ontarians.