

*Alzheimer Society*  
ONTARIO

# Pre-Budget Submission

Targeted Investments for Smarter Health  
and Long-Term Care

2020

# Targeted recommendations to better support Ontarians living with dementia and caregivers.

## Summary of Recommendations

- Invest an additional \$1.55 million in First Link® Care Navigation for a total investment of \$4.76 million, supporting 5,000 more people living with dementia and caregivers.
- Create a dedicated funding stream for dementia-specific respite services, including a targeted stream to improve access where demand for services surpasses availability.
- Fully implement recommendation 21 of the Public Inquiry into the Safety and Security of Residents in the Long-Term Care Homes System.
- Dedicate \$4 million to providing the Alzheimer Society's U-First!® training in long-term care facilities across the province.

## About the Alzheimer Society

The Alzheimer Society is a Federation of 29 community support providers, operating in every corner of Ontario. We support over 85,000 clients each year, including both caregivers 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.



# Standing with Ontarians Affected by Dementia

Dementia is a public health crisis. Urgent investments are needed to better support those affected today, and prepare for the growing number that will be affected tomorrow.

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 forms of dementia can be prevented. For the majority of those diagnosed, however, the disease causing their dementia will eventually be fatal.

Over 240,000 Ontarians live with dementia today, a number that is expected to double within the next twenty years<sup>1</sup>. Often, people with dementia are able to continue living at home, provided proper supports are available for them and their caregivers. In Ontario, nearly 60% of people with dementia live in the community, continuing to lead active lives well after diagnosis. The alternatives, hospital and long-term care, are both costlier and deliver worse outcomes for individuals who, with proper support, could continue to live at home—where they want to be.

To enable them to continue living at home, many Ontarians with dementia rely on a family caregiver, often a spouse or child, with women making up a disproportionate percentage of family caregivers. These caregivers are an integral, and often unrecognized, part of our health-care system. They sacrifice their own wellbeing to care for someone, and in doing so they save health-care systems across Canada an estimated \$25 billion each year<sup>2</sup>. Without family caregivers, our hospitals and long-term care facilities would quite simply be unable to cope.

Despite the sacrifices of caregivers, as a person's dementia progresses there may eventually come a time when admission to a long-term care facility is necessary. Nearly two-thirds of residents in Ontario's long-term care facilities have a diagnosis of dementia<sup>3</sup>, and with high staff turnover and inconsistent staff-to-resident ratios, LTC facilities are struggling. Frontline staff can be ill-equipped and insufficiently trained to interact with residents living with dementia, even with their sincere desire to provide the best care possible.

The provincial government has taken steps in the right direction, emphasizing the importance of keeping people out of hospital and in the community, and committing to build or upgrade 30,000 long-term care beds. But without concurrent investments in community supports and LTC staff training, these initiatives will only shift the problems our health-care system struggles with.

Instead, we have four recommendations to help solve them.

---

<sup>1</sup> Dementia Projections for the Counties, Regional Municipalities, and Census Divisions of Ontario. Robert Hopkins, June 2010.

<sup>2</sup> Why Canada Needs to Better Care for Its Working Caregivers. National Institute on Ageing, 2018.

<sup>3</sup> Annual Report 2019, Volume One. Office of the Auditor General of Ontario. December 2019.

## Connected Families, Connected Care

Provide additional funding for the First Link® Care Navigation program, connecting families to the supports and services they need, where and when they need it

A diagnosis of dementia is a life-altering event. Without compassionate support from individuals specifically trained in dementia care, families can be left feeling confused, overwhelmed, and scared, struggling to find out for themselves what their next steps should be. Far too often, we hear from individuals told that they have dementia, and should go home and get their affairs in order—with no advice on where to turn, and no mention that

most people living with dementia lead active, fulfilling lives for years after being diagnosed.



*"I am truly amazed at how much work they do with so few people. It seems rather magical that they are able to connect with so many people. Their staff is not very big and they serve a huge population. If anything, I would be an advocate for more of them. They do an amazing job."*

**—Jessica, medical professional in southern Ontario, referring to First Link® Care Navigators**

The Alzheimer Society First Link® program supports families at every stage of the dementia journey, working closely with our partners in primary care. Immediately following a diagnosis, physicians can refer their patients to First Link®, or individuals

can self-refer to the program. Families are then connected to a First Link® Care Navigator (FLCN), a trained professional who supports both the person living with dementia as well as their caregiver throughout the progression of the disease.

First Link® is so much more than system navigation. Caregivers are given tools and education so they can understand what to expect at every stage of the disease, building confidence and reducing illness and burnout. People living with dementia have a care plan created specifically for them, centred on their unique needs and integrating their care team around one common point person. And throughout the dementia journey, including past end-of-life, the FLCN remains connected to the family, so they never feel alone.

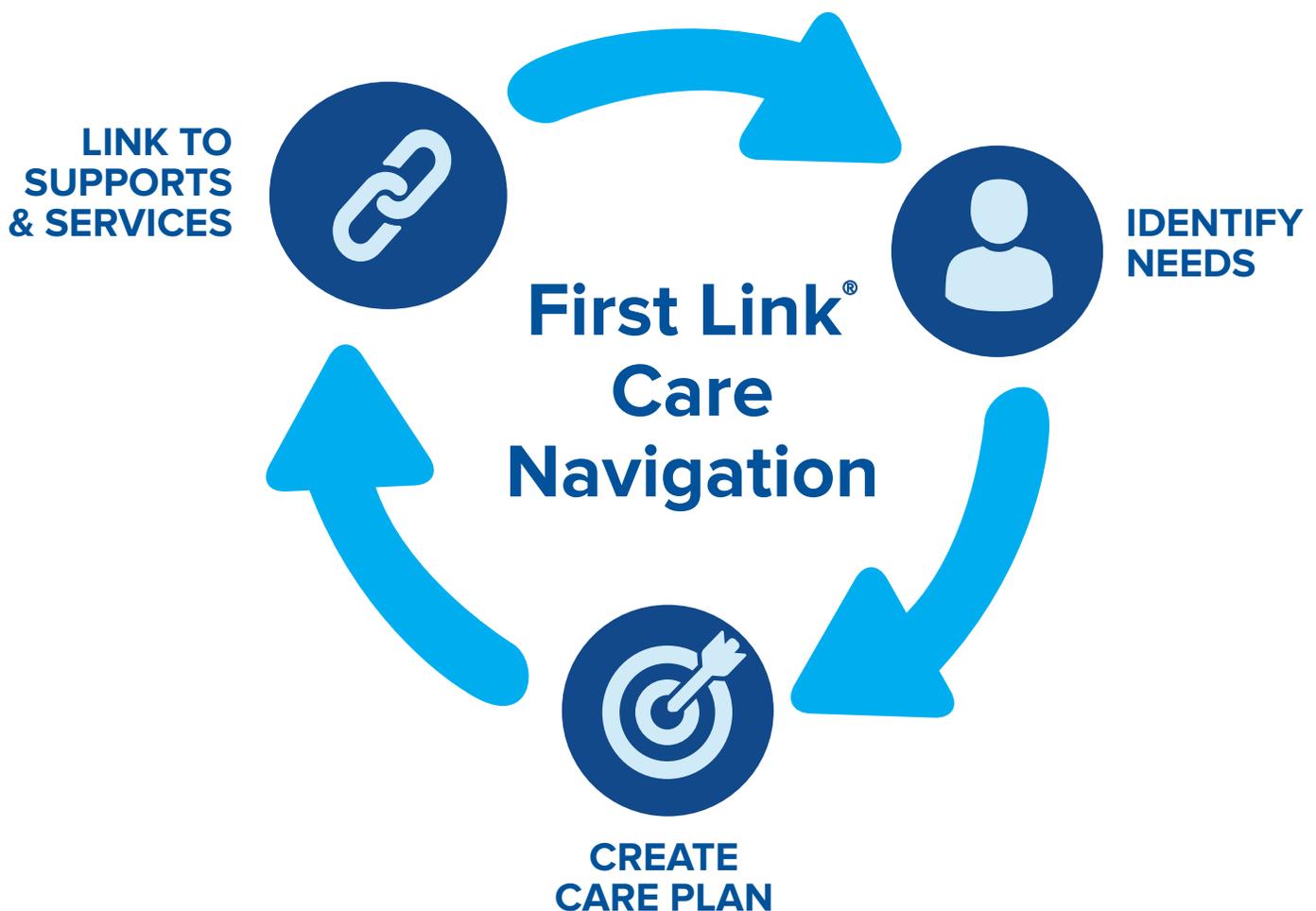
A 2012 study found that First Link® connects families with services and supports 11 months sooner than if they were left on their own. Further funding from the then-Ministry of Health and Long-Term Care in 2018/19 enabled a fulsome evaluation of the First Link® program, demonstrating its continued benefit and value. Caregivers and people living with dementia report feeling better educated, better connected, and better able to advocate for their needs thanks to First Link®. And 90% of FLCNs reported their clients felt better prepared for the future<sup>4</sup>. This adds up to cost savings downstream, with delayed admission to long-term care and a reduction in avoidable emergency room visits.

<sup>4</sup> First Link® Care Navigation Program, Evaluation Report Year 2. Centre for Community Based Research. April 2019.

There is a pressing need for greater access to and resources for the First Link® program. FLCNs are operating at capacity, and additional frontline staff would fill an immediate need. With a further investment of \$1.55 million, 5,000 more people living with dementia and caregivers would be supported in communities province-wide—increasing the total number of clients served by First Link® to over 12,000. This is an investment in delaying admission to long-term care, avoiding unnecessary hospitalizations, and most crucially, an investment in Ontario families affected by dementia.

### Recommendation:

- Invest an additional \$1.55 million in First Link® Care Navigation for a total investment of \$4.76 million, supporting 5,000 more people living with dementia and caregivers.



## Caring for Caregivers

### Act on insights from the Premier's Council on Improving Healthcare and Ending Hallway Medicine and fund additional supports for caregivers of people living with dementia

Being a caregiver is a profound act of selflessness. Caregivers sacrifice their emotional, physical, mental, and financial wellbeing to support someone they care about, often a parent or spouse. Caregivers regularly report greater levels of stress and anxiety compared to the general population.

Being a caregiver to someone living with dementia adds an additional level of complexity to the already challenging role. Caregivers of a senior living with dementia are 73% more likely to experience distress compared to those who care for other seniors, and devote over 50% more time to their caregiving role. Across Canada, family or unpaid caregivers spend

a collective \$1.4 billion of their own money on caregiving each year, sacrificing their own financial security to provide care<sup>5</sup>.



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

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

Without proper supports to manage the tremendous financial, emotional, and physical strain of caregiving, caregivers can become patients themselves, burnt out and in need of medical care.

Supports are available. The Alzheimer Society and other community support service providers offer respite programs of varying intensity, ranging from adult day programs and friendly visiting to in-home care. These respite programs are tailored to meet the unique needs of a caregiver of someone living with dementia, which differ from those of other caregivers.

Yet these respite supports are already stretched beyond their capacity. Wait times often exceed six months, and the requirement that a family be referred to some respite programs adds even more waiting time. Caregivers often report that by the time they clear a wait list, they no longer need the program they were waiting for.

When a caregiver reaches the point where they are forced to ask for help, they need that help right away. It is simply unacceptable to force them to wait half a year, or more.

<sup>5</sup> Dementia in Canada: Unpaid caregiver challenges and supports. Canadian Institute for Health Information, June 26 2018.

Additional capacity is needed in every corner of the province. Caregivers are doing more than their part, making personal sacrifices to keep their family members out of hospital or long-term care, for as long as possible—saving Canada’s health-care system an estimated \$25 billion<sup>6</sup>.

All caregivers ask in return is proper support. They deserve no less.

## Recommendation:

- Create a dedicated funding stream for dementia-specific respite services, including a targeted stream to improve access where demand for services surpasses availability.

Nearly **60%** of people with dementia live in their own home—that’s **140,000** Ontarians.

Source: Rising Tide: The Impact of Dementia on Canadian Society. Alzheimer Society of Canada, 2010.

Of those, **64%** receive some kind of community support.

Source: Rising Tide: The Impact of Dementia on Canadian Society. Alzheimer Society of Canada, 2010.

**\$36:** average cost to provide one hour of respite care.

Source: CCAC Comparative Reports. Health Quality Ontario, 2013.

**\$131 million:** cost to provide one additional hour of respite care a week, to **half** of the Ontarians with dementia living at home.

**\$655 million:** cost to provide five additional hours of respite care per week to the same number of Ontarians.

<sup>6</sup> Why Canada Needs to Better Care for Its Working Caregivers. National Institute on Ageing, 2018.

## Long-Term Vision for Long-Term Care

### Implement advice from the Public Inquiry into the Safety and Security of Residents in the Long-Term Care Homes System, and fund dementia care training for frontline and supervisory staff

Long-term care in Ontario is already stretched to its limit. Median wait times to move into a long-term care facility from the community exceed five months<sup>7</sup>, a problem that will only grow as Ontario's population ages and our life expectancy improves.

More capacity is part of the solution, and the provincial government's pledge to fund 15,000 new and a further 15,000 upgraded beds within five years is a welcome step. It will also intensify the existing challenge of recruiting and retaining enough qualified staff to care for residents, something that is already limiting bed availability, especially in Northern communities.



*"The Ministry of Health and Long-Term Care should create a new, permanent funding envelope for long-term care homes to fund training, education, and professional development for all those providing care to residents in LTC homes".*

**—Recommendation 21 of the Public Inquiry into the Safety and Security of Residents in the Long-Term Care Homes System**

Front-line staff in long-term care facilities need a wide array of skills, with frequent training to ensure they stay up-to-date on care techniques and approaches. High turnover in long-term care facilities further highlights the necessity of regular education and training.

With nearly two-thirds of long-term care residents having a diagnosis of dementia<sup>8</sup>, understanding how dementia can impact behaviour is essential for any staff member in a long-term care facility. This understanding will help frontline and supervisory staff work as a team to develop individualized support strategies for residents living with dementia, and promotes a common knowledge base, values, language, and approach to care among all staff responsible for a resident's wellbeing.

The Alzheimer Society's U-First!® program provides training in how to deliver person-centred care to someone living with dementia. It is available to both health-care professionals and caregivers, cultivating a mutual respect among the various members of an individual's care team, in addition to facilitating conversations in a common language.

<sup>7</sup> System Performance. Health Quality Ontario, courtesy of data provided by the then-Ministry of Health and Long-Term Care. 2019.

<sup>8</sup> Annual Report 2019, Volume One. Office of the Auditor General of Ontario. December 2019.

U-First!® is grounded in respect for the individual. Those trained in the program learn how to adjust their actions to better accommodate the physical, intellectual, emotional, environmental, and social needs of a person living with dementia, encouraging their independence and respecting their dignity and right to individuality.



*"Every resident has the right to be treated with courtesy and respect and in a way that fully recognizes the resident's individuality and respects the resident's dignity."*

**—Residents' Bill of Rights, Long-Term Care Homes Act**

Providing U-First!® training in Ontario's long-term care facilities is not a new idea. It was first recommended in a 2004 report to the then-Minister of Health and Long Term Care<sup>9</sup>, a report revisited by the 2019 Public Inquiry.

With the provincial government's renewed focus on Ontario's long-term care system, the time is right to equip staff with the tools and training they need to provide compassionate, dignified care.

## Recommendation:

- Fully implement recommendation 21 of the Public Inquiry into the Safety and Security of Residents in the Long-Term Care Homes System.
- Dedicate \$4 million to providing the Alzheimer Society's U-First!® training in long-term care facilities across the province.



<sup>9</sup> Commitment to Care: A Plan for Long-Term Care in Ontario. Spring 2004.

## Working Together for Better Care

Targeted investments in community supports are a step towards building a smarter, more efficient, more compassionate health-care system.

Dementia is, in many ways, a case study on the importance of having a coordinated health-care system. On any given day, a person living with dementia might interact with their care partner, a personal support worker, a First Link® Care Navigator, staff at an adult day program, and their family doctor. On the worst days, they may also find themselves interacting with a triage nurse, emergency room physician, and other hospital staff.

All these moving parts in our health-care system need to cooperate and collaborate seamlessly, to provide the care Ontarians deserve and expect. Providers must each have a well-defined role to play, and they need to be adequately funded to fulfill that role. When this doesn't happen, patients end up receiving a level of care that is either above or below what they need, wasting public funds and diminishing the quality of care for that patient.

By acting on our pre-Budget recommendations, the Government of Ontario would be demonstrating its commitment to efficient, compassionate care and support for people living with dementia and their care partners.

The Alzheimer Society is excited to contribute to building a more dementia-friendly health-care system. ***Together, we can build a dementia care system that works.***

