

# SUPPORTING ONTARIO FAMILIES LIVING WITH DEMENTIA



Building a dementia care system that works –  
for families and the economy

## 2019 PRE-BUDGET SUBMISSION

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# When it comes to dementia, Ontario families are facing a breaking point. So is our health care system.

The number of people living with dementia in Ontario will surpass a quarter of a million by 2020.<sup>i</sup> **Over the next 20 years, that number is expected to double and the impact on our healthcare system will be enormous.** Wait lists for long-term care and more families in crisis will lead to unnecessary hospital usage, which contributes to the issue of hallway healthcare. The only solution is enhanced support in the community for people living with dementia, including the vital services of the Alzheimer Society.



**People living with dementia have the right to live the best life possible – in the place of their choice –** with dignity and quality care. But far too often, they lack the supports and services they need to stay socially engaged, maximize quality of life, and remain at home and in the community.

**Family members are willing care partners, but they are not getting the support they need.** It is taking a toll on their mental and physical health, quality of life, and ability to continue caring. Without the right help, many have no choice but to turn to long-term care or unnecessary hospital stays.

**Hospitals and long-term care are stretched beyond their limits.** Health care costs are estimated to be 5½ times higher for a person living with dementia.<sup>ii</sup> It costs far less to provide care in the community, but the role of unpaid care partners cannot be taken for granted. Investment in community-based supports and services is critical.

**We need to build a dementia care system that works for families, is not complicated by unnecessary red tape, and makes the best use of health care dollars.**

Cost-effective investments that promote and enable living at home are vital to help solve the challenges of hallway healthcare and long-term care capacity. They are also essential for the quality of life of Ontarians impacted by dementia.

# Dementia is an issue that matters to the people of Ontario.

A survey conducted in June 2018 among Ontarians 50+ revealed that dementia is the top concern that people have about aging.<sup>iii</sup>

For people living with dementia and the family members and friends that care for them, it matters even more. Over the past two and a half years, more than 10,000 Ontarians have written letters to MPPs to ask for greater investment to address the gaps in services and care that are critical for people living with dementia to continue living in the community. Thousands more have participated in consultations to share their views or met directly with MPPs.

ONTARIANS SAY  
THAT DEMENTIA IS  
THEIR #1 CONCERN  
ABOUT AGING

ONTARIO FAMILIES  
IMPACTED BY  
DEMENTIA ARE NOT  
GETTING THE SUPPORT  
THEY NEED

Many effective programs and services exist today, but they are stretched to capacity.

In October 2018, the Alzheimer Society Action Summit brought together people living with dementia, care partners, and local Alzheimer Societies that deliver front-line services across Ontario. Their message was clear: **More needs to be done. Not later, but now.**

**The system is confusing to navigate. Care partners are burning out. Unnecessary admissions to hospitals and long-term care are wasting tax dollars.** Life can have meaning, progression can be slowed after a diagnosis, and families can continue caring at home – if the right supports are provided.

## What are the biggest needs?

1. **SYSTEM NAVIGATION:** One go-to place for families that offers direct support and makes it easier to connect to services and programs early on – before crisis hits: Alzheimer Society First Link®.
2. **COMMUNITY SUPPORTS AND PROGRAMS:** Access to Alzheimer Society education, social/recreational programs, and individual/group support.
3. **RELIEF FOR CARE PARTNERS:** Adult day programs and in-home respite so that family care partners get a break and can continue caring longer.

# Dementia is taking its toll on families and the economy.

Most dementia care is provided in the community, where family members have assumed the role of unpaid care partner. Many are part of the “sandwich generation” that are caring for their children and parents at the same time. **Too much pressure is being placed on the unpaid workforce.**

Over 60% of people living with dementia in Ontario live in the community and that number grew by 46% between 2009/10 and 2015/16.<sup>iv</sup> Long-term care has shifted to serve those with higher needs, making community dementia care more complex.

While home care and community support service investments have increased in recent years, it is still not enough. **Many care partners struggle with emotional stress, depression, physical strain and exhaustion, their own illnesses and financial burdens.**

“A caregiver must be given care, or you will end up with two patients.”

*Care partner, Sault Ste. Marie*

The percentage of care partners reporting distress, anger or depression in relation to their caregiving is rising and Ontario’s rate is the highest among all provinces with comparable data.<sup>v</sup> The impact is even greater for care partners of people living with dementia.

The negative effects of stress on a care partner’s health can range from anxiety, depression, and migraines<sup>vi</sup> to early death<sup>vii</sup>. Nearly half of dementia care partners experience distress and more than 20% feel unable to continue caring at home due to stress.<sup>viii</sup>

Too often, care partners are faced with an impossible situation as they confront increasing pressure to balance work and care. This often results in absenteeism, reduction of employment hours to part-time, or premature exit from the labour force. This has implications for the financial security of families, and impacts employers, labour market sustainability, and the overall economy.

People living with dementia have higher care needs. **It is estimated that dementia will cost Ontario close to \$325B in health-related and other costs from 2008 to 2038.<sup>ix</sup> This makes it even more important to ensure that we build a cost-effective dementia care system.**

**45%**

of Canadian dementia care partners face **distress**

**\$11B**

in **lost income** for care partners in Canada

**\$325B**

**Cost of dementia** in Ontario (est. 2008 -2038)

# Smart health care investments will reduce the demand for higher-cost long-term care and address hallway healthcare.

## Delayed long-term care means that more people can access long-term care when they need it most.

Community-based interventions including case management, care partner education, counselling, and support groups have been shown to delay or prevent admission to long-term care.<sup>x</sup>

In some studies, a combination of individual and group counselling, care partner education and support groups resulted in a 12%-18%<sup>xi</sup> reduction in the rate of long-term care admission and delayed long-term care placement by more than 11 months.<sup>xii</sup>

A long-term care study from the Canadian Institute of Health Information found that “reducing each new client’s length of stay by just 1 month could enable nearly 1,000 more people to be served without increasing capacity”.<sup>xiii</sup>

## The right community supports can help address hallway healthcare.

When families are in crisis or behavioural symptoms intensify, the risk of preventable hospital admissions increases. This not only creates unnecessary health care costs, but also causes deterioration of dementia symptoms or increased risk of delirium, falls or health complications.<sup>xiv</sup>

ALC (alternate levels of care) beds in hospitals are a key concern when it comes to the issue of hallway healthcare, with average costs of \$730 per day<sup>xv</sup>. Hospital stays for people living with dementia are longer and costlier.<sup>viii</sup> Research has shown that when families receive a range of in-home and community supports, hospital stays for people living with dementia are shorter.<sup>xvi</sup>

**Community programs and services can help keep people living with dementia at home and out of hospitals, where they can have greater dignity and quality of life at lower cost.**<sup>xvii</sup>

“I can’t believe I thought my Mom needed to move into a home. There is so much we can do to support her at home.”

*Care partner, Niagara Region*

## COST EFFICIENCY OF COMMUNITY DEMENTIA SUPPORTS

Evidence: Combination of counselling, care partner education and support groups has been shown to **delay long-term care placement by 11+ months**

Typical annual cost for Alzheimer Society to deliver this combination of services for one client  
**\$1100**<sup>xvii</sup>

Potential costs savings per client if LTC placement is delayed by 11 months (based on LTC cost of \$150/day<sup>xv</sup>)  
**\$50,000**

# Phyllis' Story: Living with Dementia

Phyllis Fehr, former ICU nurse, advocate, and person living with dementia.

*I first started to see symptoms in my late 40's and, being a registered nurse, I had a good idea about what those symptoms might be. I knew that getting an early diagnosis and intervention were key. But getting a formal diagnosis was a long and challenging process. It did not happen until I was 52.*

*At that point, the physician no longer spoke to me but, instead, spoke to my husband. We weren't given any advice or referred to any supports or services. We were not offered any hope. We were told, simply, to go home and get our affairs in order. It was like being kicked in the stomach.*

*By the time I received a diagnosis I was in a fog. I was having difficulty finding words and multi-tasking and began to withdraw from social activities. But I was one of the lucky ones—medication helped get me out of the fog and I was able to return, somewhat, to my former life.*

*Yet a lot has changed, not only in my own life, but in my family's. Just as I was prescribed a new identity when I received my diagnosis, so too was my husband, who in that moment became not only "husband" and "father" but now, "care partner" too. Over time, he's taken on more and more household tasks that I can no longer manage. He has made my care and wellbeing a priority, even when struggling with his own health. This is what being a care partner is—it's sacrifice, it's changed relationships and a new job that you were never trained for or prepared to do. My husband is my greatest supporter, but he, as care partner, needs to be supported too.*

*When I received my diagnosis I had two very strong emotions: the first being relief because I had started questioning if I was imagining things or if I was having mental health issues. The second was, "What now?". After watching my grandmother, my mom, and all my aunts have dementia and not knowing where I could turn for support, I thought my life was over.*

*It took a year before I finally said I was not taking this sitting down. That's when I became involved with the Alzheimer's Society. They brought hope. But this hope should have come sooner. First Link® is an Alzheimer Society program that works to connect people early, ideally at the point of diagnosis, to their local Society. Once registered, people living with dementia and care partners are connected to the supports, education, and community services they need. Without support from the Alzheimer Society, I don't know where I or my family would be.*

*Getting a diagnosis of dementia is hard. Without support, it's harder. When people receive the support they need, are connected to services, and are educated about their diagnosis and what to expect, they do better. Like me, they can live full, active, healthy lives and remain independent for longer.*

*Almost every Ontarian's life has been touched by dementia. We all want and deserve to live well and, with your support, we can.*

# The Care Partner Experience.

## **Dede – wife and care partner**

*“I’ve got my mind around the fact that my husband and I won’t have a social life together, and that we can no longer travel together. Our normal life is gone.”* Being a care partner for her partner has led Dede through the medical system in an attempt to find adequate support for both her husband and herself. Her experience has been punctuated by closed doors, as her husband’s condition is not yet bad enough to warrant the support of home care in her region. Like many care partners, Dede is feeling the weight of her husband’s diagnosis.

*“I’m exhausted all the time. Scratch the surface and I am physically, emotionally and mentally weary and I’m only at the beginning of the journey. I’m scared and frustrated. There’s way too much burden put on untrained caregivers.”*

## **Corene – daughter of father who is living with dementia**

*“My mother has often said that she lost both her husband and herself. Her life became about her husband’s care. She couldn’t take part in her book club, walking group, or go out and spend time with her children or grandchildren. She was isolated by her role as a care partner, and she lost her identity.”*

## **Chris – son of mother who is living with dementia**

Chris lives with his mother Lori, who is showing signs of dementia. Chris was already experiencing financial stress and low income, and quit his job after receiving advice from his doctor to do so given the complex needs of his mother and related stress. After being linked with the First Link® Care Navigator at his local Alzheimer Society, Chris and his mother now have supports from a variety of agencies and have a proactive plan in place which has led Chris to secure new employment, easing his financial stress.

# Early diagnosis and early connection to support is critical.

A diagnosis of dementia is difficult. Many families don't know what services are available or how to access them. **It is well recognized that early diagnosis and intervention can have a strong positive impact on quality of life and care partner capacity, and even slow progression of the condition.**

**Alzheimer Society First Link® is the only province-wide service of its kind in Ontario.** It gives people living with dementia and their care partners a single access point, so they can get the supports and care they need as early as possible – before they reach crisis. First Link® also provides relief to physicians by providing a place to refer their patients for immediate help after diagnosis.

Recent investment in First Link® was in response to feedback from thousands of Ontarians. First Link® Care Navigators are now working in all 29 local Alzheimer Societies, providing individual assessment, care planning, follow up, and coordination of services across providers and sectors. This case management approach has been associated with reduced admissions to long-term care.<sup>x</sup>

**An additional 22 front-line First Link® Care Navigator positions are required to meet current demand and achieve:**

- Increased care partner capacity to care at home
- Stronger linkages across all sectors of the dementia care system
- Clearly defined referral pathway to local services
- Greater dignity and quality of life

When primary care physicians refer families to First Link®, it results in connection 11 months sooner than self-referral.<sup>xviii</sup> But people are often diagnosed too late – or not diagnosed at all. Not all providers know that high quality services and supports are available to people after a diagnosis.<sup>xviii</sup> Investment in primary care education and memory clinic models that are effective in early diagnosis and referral to First Link® is urgently needed.

*“I had no idea these programs existed. I thought moving her into a home was the only option.”*

*Daughter, care partner and First Link Care Navigation client*

**Recommendation:** Ensure that Ontarians living with dementia and their families have early access to **First Link® Care Navigation** so they can connect to the community supports and care they need – before crisis hits.

1. Increase annual base funding for **Alzheimer Society First Link® Care Navigation** from **\$2.9M** to **\$4.8M** for front-line service staff
2. Enhance **primary care dementia education** (from medical school through continuing education) and support training for Primary Care Collaborative Memory Clinics

# Alzheimer Society programs & services are vital for Ontarians.

**The Alzheimer Society is often described as a “lifeline” for people living with dementia and their families.**

More than 70,000 Ontarians receive direct service from local Alzheimer Societies each year. They benefit from information, education, programs, and support from diagnosis and throughout the dementia journey.

But the number of people living with dementia in the community is growing rapidly and more families are seeking support. Local Alzheimer Societies across the province are stretched to capacity and are struggling to keep up with the demand for these vital programs and services that help people remain at home, delaying or avoiding the need for long-term care.

The Alzheimer Society services play a unique and critical role in the community dementia care system:

- Care partner education that builds knowledge, skills and capacity including dementia care, risk management, coping strategies and resiliency, planning, and personal stress management
- Support groups and programs that increase social engagement and reduce isolation of people living with dementia and care partners
- Social/recreational programs that can help slow the progression of dementia, maintain quality of life, and promote celebration of life through meaningful engagement
- Integration with other community-based service providers to meet client needs

“We dance, we laugh, we even yell sometimes. We don’t always remember each other’s names, but we don’t feel bad about that. It feels so good to have friends again”.

*Mother, wife and First Link client,  
living with dementia*

**Recommendation:** Meet the growing demand for vital **Alzheimer Society programs and services** that give people living with dementia and their families the knowledge, skills and support they need to live the best life possible in the community.

- Ensure that local Alzheimer Societies have the funding they need to keep pace with growth in dementia prevalence, incoming referrals, and demand for education programs, individual and group support and social/recreational programming

# Family care partners need a break to continue caring.

Stress and burnout among care partners of people living with dementia can be much better managed when they have respite – a break that gives them time to take care of their own health, work, manage personal tasks, or simply rest.

Both out-of-home and in-home respite programs can help reduce the risk of crisis situations that can lead to hospitalization or premature admission to long-term care. **But far too often, care partners cannot access the respite support they need.**

Adult day programs keep people living with dementia active and engaged – which can slow progression – and give care partners a much-needed break. In this way, adult day programs offer a “2 for 1” value for every dollar spent.

Home care is also essential for personalized care of people living with dementia and the support of care partners in their role.

But in Ontario today, adult day programs and home care are not flexible enough – or are not available at all. Day program wait times are often up to six months and can be difficult to access due to transportation and lack of evening/weekend options. Families often face red tape in qualifying for home care, and there is limited choice when it comes to home care scheduling, services, and providers. In addition, there is a severe labour shortage of personal support workers that can mean support is simply not available.

High quality dementia-specific program design and training are also critical. Front-line staff must have the knowledge and skills to support the social and behavioural needs of people living with dementia.

ADULT DAY PROGRAMS  
AND IN-HOME RESPITE  
HELP PEOPLE WITH  
DEMENTIA TO REMAIN  
AT HOME LONGER

**Recommendation:** Reduce red tape and increase access to **dementia adult day programs and in-home respite** to ensure that care partners can avoid burnout and continue caring at home.

- Increase capacity of dementia-specific adult day programs and in-home respite supports
- Remove barriers to access and ensure that respite care meets the social, recreational, behavioural and care needs of people living with dementia:
  - Cover day program transportation costs and expand evening and weekend hours
  - Give families more choice and flexibility for in-home respite scheduling, services and providers
  - Implement human resource strategies to recruit and retain personal support workers
  - Provide quality dementia training for all front-line health care workers to build the knowledge and skills needed for positive client experience and behavioural supports

# SUMMARY OF RECOMMENDATIONS

- 1) SYSTEM NAVIGATION:** Ensure that Ontarians living with dementia and their families have early access to **First Link® Care Navigation**, so they have direct support to connect to the community supports and care they need – before crisis hits.
  - Increase investment in Alzheimer Society First Link® Care Navigation from \$2.9 million to \$4.8 million in annual base funding for **front-line service staff**
  - Enhance primary care education (from medical school through continuing education) and support training for Primary Care Collaborative Memory Clinics to ensure timely, accurate diagnosis and immediate First Link® referrals
  
- 2) COMMUNITY SUPPORTS:** Meet the growing demand for vital **Alzheimer Society programs and services** that give people living with dementia and their families the knowledge, skills and support they need to live with dignity and quality of life in the community for as long as possible.
  - Ensure that local Alzheimer Societies have the base funding they need to keep pace with growth in dementia prevalence, referral growth and demand for education programs, individual and group support, and social/recreational programming
  
- 3) RELIEF FOR FAMILIES:** Increase access and reduce red tape for **dementia-specific day programs and in-home respite** to ensure that care partners can avoid burnout and continue to provide care at home.
  - Increase capacity of dementia-specific adult day programs and in-home respite supports
  - Remove barriers to access and ensure that respite care meets the social, recreational, behavioural and care needs of people living with dementia:
    - Cover day program transportation costs and expand evening/weekend hours
    - Give families more choice and flexibility for in-home respite scheduling, services, and providers
    - Implement human resource strategies to attract and retain personal support workers
    - Provide quality dementia training for all front-line health care workers to ensure they have the knowledge and skills needed for positive client experience and behavioural supports

# An efficient and effective dementia care system for Ontario.

The Alzheimer Society is committed to working with the Ontario government – as an advisor, partner, and service provider – for a better, more efficient dementia care system.

With support of our 2019 budget recommendations, we will work with government to help cut red tape in our health care system, streamline reporting, ensure that every dollar invested delivers the best possible impact, and break down silos across sectors that can get in the way of good care.

The Alzheimer Society plays a unique role as the only province-wide community-based provider that is there to provide direct support to people living with dementia and their care partners from the moment the dementia journey begins. We know that Ontarians see us as a partner they can trust.

We have unique dementia care expertise and strong linkages with the health and community support sectors in every Ontario community and we play a key role in more efficient, integrated care across all sectors – clinical, institutional, community, and beyond.

The Alzheimer Society also supports the 2019 Budget Submissions of the Ontario Caregiver Coalition, Ontario Community Support Association, and Dr. Linda Lee’s submission for Multispecialty Interdisciplinary Team (MINT) Memory Clinics.

**Together, we can create an efficient and integrated dementia care system that gives Ontario families impacted by dementia the support they deserve.**

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