



FIRST LINK IMPACT REPORT 2017

Meeting the needs of an aging Ontario



A diagnosis of dementia is shocking.

FIRST LINK[®] MAKES IT EASIER.

This report outlines the growth of First Link and how it is helping Ontario respond to our aging population and growing prevalence of dementia.





228,000 Ontarians
living with dementia



Expected to
double
in next 20 years



41,000

First Link
clients served in
2016-17

A **lifeline** for people living with
dementia and their care partners



First Link referral rate has
doubled since 2011

● 2011 ● 2017

More families accessing
supports and services
as soon as possible
after diagnosis



25,000
referrals in 2016-17



Stronger linkages with
healthcare providers
including
primary care



30 local
Alzheimer
Societies

Supporting clients in
communities across **Ontario**



First Link®: A first step to making connections, building knowledge, and accessing support

First Link is a program of the Alzheimer Society that connects people living with dementia and their care partners to the information, supports and services they need, as early as possible and throughout the progression of the condition.

Individuals and families affected by dementia often feel overwhelmed by the road ahead. Many find it difficult to ask for help, or find it challenging to understand the system and find the supports they need.

First Link makes it easier.



I feel more hopeful now. At first the diagnosis seemed dire. But when the Alzheimer Society called they always said you're not alone, you're not alone, you're not alone... and that's how I feel."

Person living with dementia

By connecting to education and supports early, First Link enables individuals and care partners to feel more confident and empowered to make decisions regarding their quality of care.

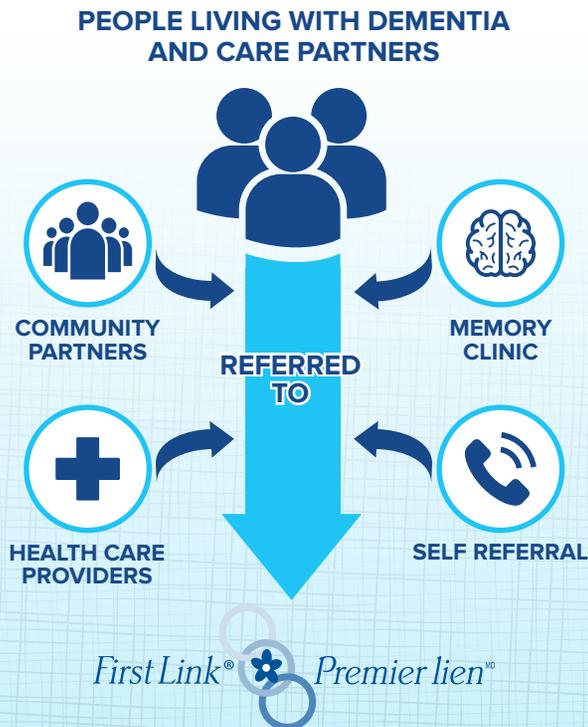
How does First Link® help?

Connecting Families to the Alzheimer Society

Many families are told about the Alzheimer Society and dementia care services, but will not make the call until a crisis occurs. First Link helps to remove this barrier by enabling physicians, other health care providers and community service providers to directly refer individuals and families at the time of diagnosis or as soon as possible after a diagnosis is made.

Connecting Families to Services and Support

When people living with dementia or their care partners make contact with the local Alzheimer Society, First Link helps them to identify and access the information, supports and services that meet their unique needs. First Link facilitates connections to education, programs and services offered by the Alzheimer Society, as well as other health care and community service providers. It's a person-centred approach that supports individuals and families to get the support they need – when they need it.

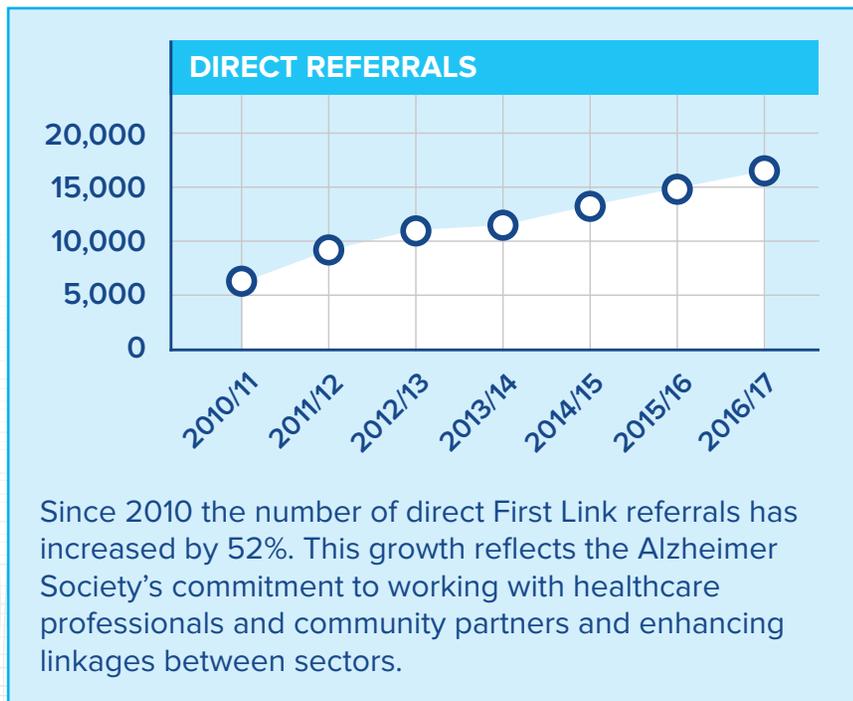


Healthcare Partner Referrals Connect People to First Link® faster

Connecting to the right supports early in the dementia journey can make a big difference in the quality of life for people living with dementia and their care partners.

A study has shown that people who were referred directly to First Link by healthcare professionals (direct referrals) received services and supports **11 months sooner** than clients who accessed the services themselves (self-directed referrals). In 2016/17 there were 16,000 referrals from health care and community partners.

First Link helps to bridge gaps between providers in the circle of care. By creating robust partnerships across primary care, community care and the community support services sector, First Link ensures that individuals and families get support as early as possible and have better coordinated care.



More than half of First Link® clients are directly referred by healthcare professionals and other community partners.

Primary Care	12%
Specialized Care	24%
Acute Care	4%
CCAC	13%
CSS	7%
Other community partners	4%
Self-referral	36%

64% of total First Link referrals

Collaboration with Primary Care to Enhance First Link® Impact

First Link's success in Ontario proves the effectiveness of care models based on partnerships between sectors and interdisciplinary care.

One partnership that has improved access to service and supports for those living with dementia and their care partners is the integration of First Link with primary care collaborative memory clinics in Ontario. This approach means that an interdisciplinary team – including physicians, social workers, pharmacists, nurses and others - is working together to support the medical, social and community care needs of individuals and families at the time of diagnosis.

A study assessing the impact of having Alzheimer Society staff working within eleven memory clinics located in central and southwestern Ontario showed:



- Improved patient access to information and supports at the time of diagnosis



- Increased healthcare provider awareness of available community services



- Fivefold increase in direct First Link referrals in 6-month study period



Our Alzheimer Society staff member has patiently helped with sharing of her years of knowledge with us. To see the difference in our clients and families that have been returning with their follow up appointments has been amazing.

Memory Clinic Staff

First Link[®]: Improving quality of life for people living with dementia

First Link plays a crucial role in supporting the growing numbers of Ontarians facing a dementia diagnosis. The Alzheimer Society provides ongoing support to clients throughout all stages of the journey.

When an early connection is made to First Link, people living with dementia have a greater opportunity to have a voice in their current and future care. It also opens the door to support programs and social or recreational activities that can help to improve quality of life, slow progression of the condition, or enable them to live longer at home or in the community.

In a 2015 evaluation of six Alzheimer Societies, findings from a survey of persons living with dementia who had been involved with the Alzheimer Society showed:

- They had more skills and ability to cope with dementia because of the Alzheimer Society
- They felt more confident in their ability to live well
- They accessed other resources within the community



Getting a dementia diagnosis is overwhelming. It's hard to know what the next step is. The Alzheimer Society First Link program was extremely helpful. It allowed my family to learn about the services and programs we could access and helped us make informed decisions for our life moving forward."

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



■ First Link®: A lifeline of support for care partners and families

Research has shown that people caring for someone living with dementia provide **75%** more care hours than other care partners and experience nearly **20%** greater stress (Health Council of Canada 2012).

A key component of First Link is to provide direct support to care partners and families, often through the support and education programs offered by the Alzheimer Society.

By connecting with the Alzheimer Society, care partners and family members have indicated increased understanding of the disease, decreased worry, and increased feelings of relief. One care partner explained that her children feel a “weight off their shoulders” in knowing that their parents are receiving professional support. A person living with dementia explained that “it is comforting that [my husband] has somewhere to go that he can get help because he’s very quiet and he suffers in silence”.

A recent evaluation of six Alzheimer Societies showed that caregivers who are involved and active with their local Alzheimer Society:

- Felt better able to advocate for the needs of the person they are supporting
- Had more skills to cope with life’s challenges
- Expressed the Alzheimer Society helped them in times of need

“

I wouldn't have made it without them [staff at the Alzheimer Society], although I had people coming and telling me what to do – I think these people understood the disease better than anyone else and I think that they were able to assist in the care of [the person with dementia].

Care partner

First Link® leads to an increased ability to navigate the health system

Families impacted by dementia often express that the health and community care system is hard to navigate. It can be hard to know what supports are available and most appropriate for their needs; or how to connect with these supports.

Clients who participated in a recent evaluation of 8 Alzheimer Societies explained that staff at the Alzheimer Society often act as advocates as they navigate a complex system. First Link helps care partners and persons with dementia to access the services that they need, which can be intimidating or confusing for them to do on their own.



They've just been so helpful in telling us about all the programs and things that we could access to learn more about Alzheimer's and what we need to be doing. I didn't know a lot about the services out there. It's really opened the doors for us...We wouldn't have known otherwise"

Care partner

84.6%

of people living with dementia and care partners reported that they were better able to manage the challenges of dementia due to First Link and the Alzheimer Society.

(2016 First Link Evaluation)

Ontario Government invests in First Link® Enhancement

2017 was an important year for people affected by dementia in this province as the Ontario Government committed **\$101M over 3 years for an Ontario Dementia Strategy**, including \$8.15M to expand and enhance First Link.

New First Link funding will help enhance the critical role that local Alzheimer Societies play in ensuring Ontarians living with dementia and their care partners are connected to the support, services and resources they need – as soon as possible after diagnosis.

The system is challenging to navigate. Accessing support early can make a difference. This investment will enable the hire of First Link Care Navigators in local Alzheimer Societies to achieve the following impact:

- Quality of life for people living with dementia
- Greater care partner capacity and well-being
- Stronger linkages between primary care and community supports & services

WHAT DOES THIS INVESTMENT MEAN?





Alzheimer Society
ONTARIO

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