




FIRST LINK[®]
IMPACT
REPORT
2019

A first step to making connections, building knowledge and accessing supports



Alzheimer Society
ONTARIO

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

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.

Often, those just diagnosed or living with Alzheimer's disease or another dementia and those close to them feel overwhelmed and do not know where to turn for help.

FIRST LINK® MAKES IT EASIER.

Connecting to the right supports early in the dementia journey can make a big difference in the quality of life for both the person diagnosed and the care partner.

With locations all across Ontario, the Alzheimer Society and its First Link® program makes connections to vital dementia **information, support and services** helping to build confidence for the journey ahead.

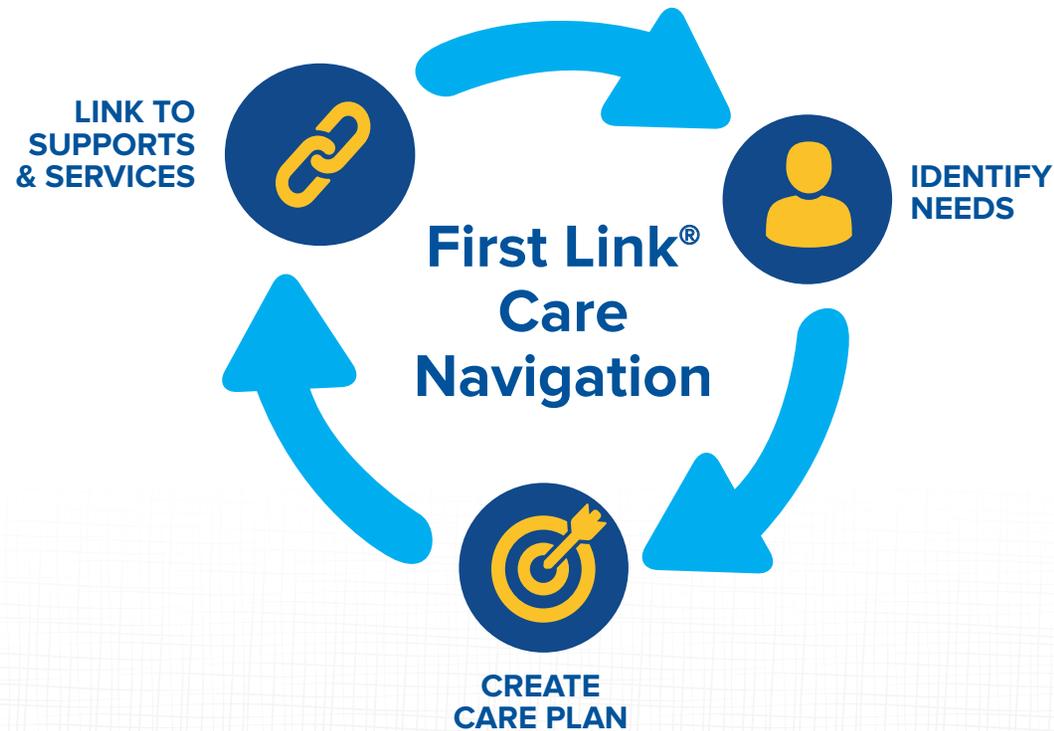
FIRST LINK® PROVIDES:

- Ongoing access to information, support and services
- System navigation
- Increased knowledge and confidence to live well with dementia
- Better health and quality of life outcomes
- Decreased care partner stress, burnout and health complications
- Reduced feelings of isolation
- Potential ability to live safely at home longer
- Fewer and less intense crises



With First Link® Care Navigation supports available across all 29 local Alzheimer Societies in Ontario, First Link® also helps clients navigate what can sometimes be an overwhelming health-care system. New First Link® funding provided by the Government of Ontario has helped to enhance the critical role that local Alzheimer Societies play in ensuring Ontarians living with dementia and their care partners are connected to the supports and services they need – as soon as possible after diagnosis.

Alzheimer Society staff will work with clients to determine their needs, create care plans that will help make things easier and make links to individualized supports and services that are agreed to. With ongoing support, clients will not feel alone.



Our Alzheimer Society staff member has patiently helped with the 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

Collaboration with primary care to enhance First Link® benefits people living with dementia and care partners

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.

First Link® partners include family physicians, geriatric specialists, nurses, social workers, occupational therapists, pharmacists and social service workers who work in family practice, health-care facilities and community agency settings.

HEALTH-CARE PARTNER REFERRALS CONNECT PEOPLE TO FIRST LINK® FASTER

A study has shown that people who were referred directly to First Link® by health-care professionals (direct referrals) received services and supports 11 months sooner than clients who accessed the services themselves (self-directed referrals).¹

REFERRING TO FIRST LINK® IS EASY:

It's easy – with consent, a referral can be sent for the person with dementia or care partner **or both** to your **local Alzheimer Society**. Although referring early/at time of diagnosis is optimal for patient benefit, connecting to the Alzheimer Society can occur at **any point** of disease progression.

Since 2010, the number of direct referrals has increased from 7,000 to over 18,500 per year. This growth reflects the Alzheimer Society's commitment to working with health-care professionals and community partners and enhancing linkages between sectors.

¹ McAiney CA, Hillier LM, Stolee P, Harvey D, Michael J. 'Throwing a lifeline': the role of First Link® in enhancing support for individuals with dementia and their caregivers. *Neurodegen. Dis. Manage.* 2 (6), 623-638 (2012)

“I have been using and promoting the First Link® program for many years. As someone who sees a lot of patients with dementia, I have found the program to be extremely beneficial for patients, families and care partners. The coordinators/navigators assist with education, counselling and connecting people to the available community resources. I know that when I make the referral, that there will be a comprehensive assessment of the patient and their personal needs at that point in the illness, and on-going support tailored to the changing situation.”

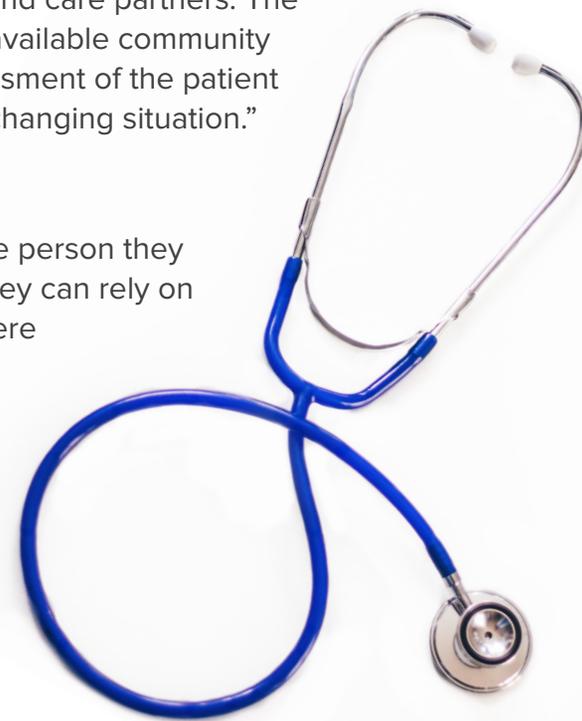
Dr. G. McKercher, Physician

“Families are better able to cope because caregivers understand what is happening to the person they are caring for. They feel more supported because now they have a few options; people they can rely on if stressed or in need. For the person with dementia, it’s the programs they can get out there and engage in which improve their quality of life.”

Medical Practitioner, Eastern Ontario

“...I have been nursing for three decades and never used to see a referral from a doctor saying refer to the Alzheimer Society. They are finally realizing that this is an actual treatment or service that should be presented as a referral.”

Medical Practitioner, Northeastern Ontario



FIRST LINK® PROVIDES REFERRAL PARTNERS:

- A simple referral system – for the person with dementia and/or the care partner
- Patient support between clinical visits
- Ability to focus on medical management
- Fewer office visits related to preventable issues
- Knowledge that patients are connected to the supports they need



240,000 Ontarians
living with dementia



Expected to
double
in next 20 years



85,941

First Link®
clients served in
2018-19

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



First Link® referral rate has
doubled since 2011

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



28,000
new referrals received
in 2018-19



Stronger linkages with
health-care providers
including
primary care



Local
Alzheimer Societies
available **near you**

Supporting clients in
communities across **Ontario**



Lili was experiencing burnout while caring for her husband.

Her husband was progressing rapidly and a friend suggested she call for help to learn what was available to keep him at home.

The Alzheimer Society staff provided an assessment and explained what services were available to assist them both. “I did everything she said I needed to do. He is now in day program and has been at a weekend away so I am able to get some time to myself. I am attending a support group and education they offer.

We are managing quite well, and I can see me being able to keep going and have him at home for much longer. My children have met with her as well and are understanding the disease better and are now offering me help in a good way and spending quality time with their dad. I know she helped me to keep my husband at home and out of the hospital.”

Angela was faced with many hardships along with her dementia diagnosis.

She could not pay her rent, her Ontario Disability Support Benefits (ODSP) were cut off, she was rejected from a subsidized retirement home because of dementia and she was at significant risk of becoming homeless.

The First Link® Care Navigator advocated and coordinated a solution across many system partners helping Angela move into a retirement home, having her ODSP benefits resume and helping to improve her quality of life.

Angela expressed her appreciation:

“ *Keep doing good work for everybody – it’s amazing what you’ve done to help me.”*

Increased dignity, choice and flexibility to live the best possible life for people living with dementia and their care partners.

As a part of Alzheimer Society of Ontario's commitment to strengthening its First Link® Care Navigation program, robust monitoring and evaluation were completed in collaboration with the Centre for Community Based Research.

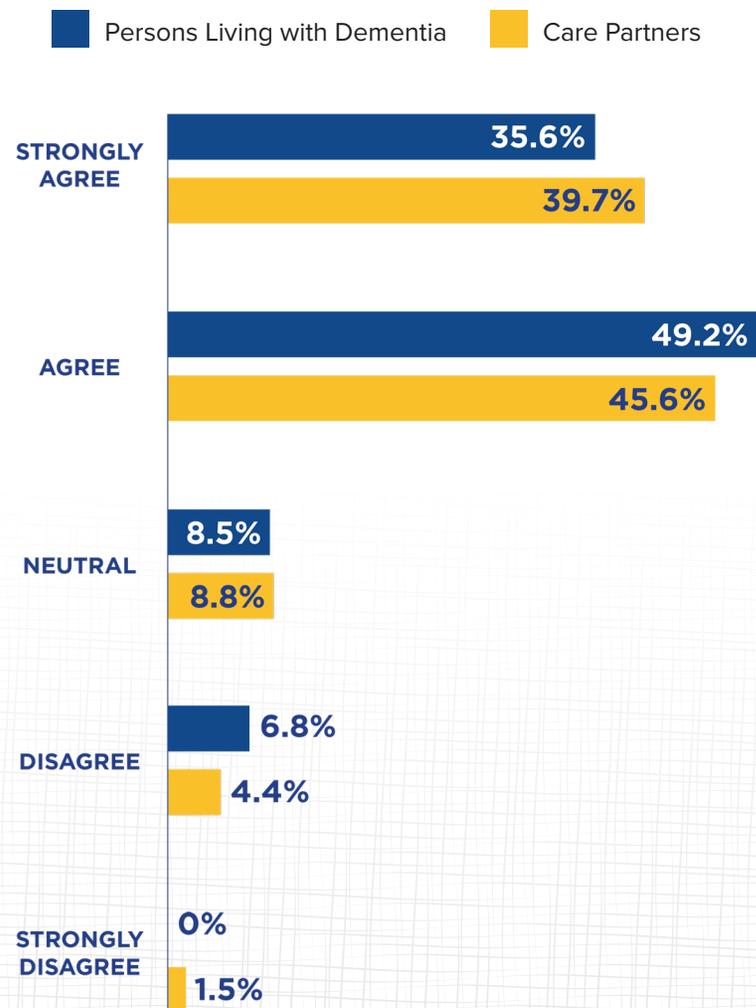
Direct client surveys, focus groups and client impact stories along with community provider interviews demonstrate that new First Link® Care Navigators, along with the Alzheimer Society team, are helping clients to live their lives according to their own preferences and are achieving better quality of life outcomes.

“ Again, thank you so much for your kindness, support and facilitating this long and daunting process. I was honestly choking back the tears when we spoke, and you've helped my family and myself more than I can say. As soon as you got in touch with me, everything started to improve.” — care partner, daughter

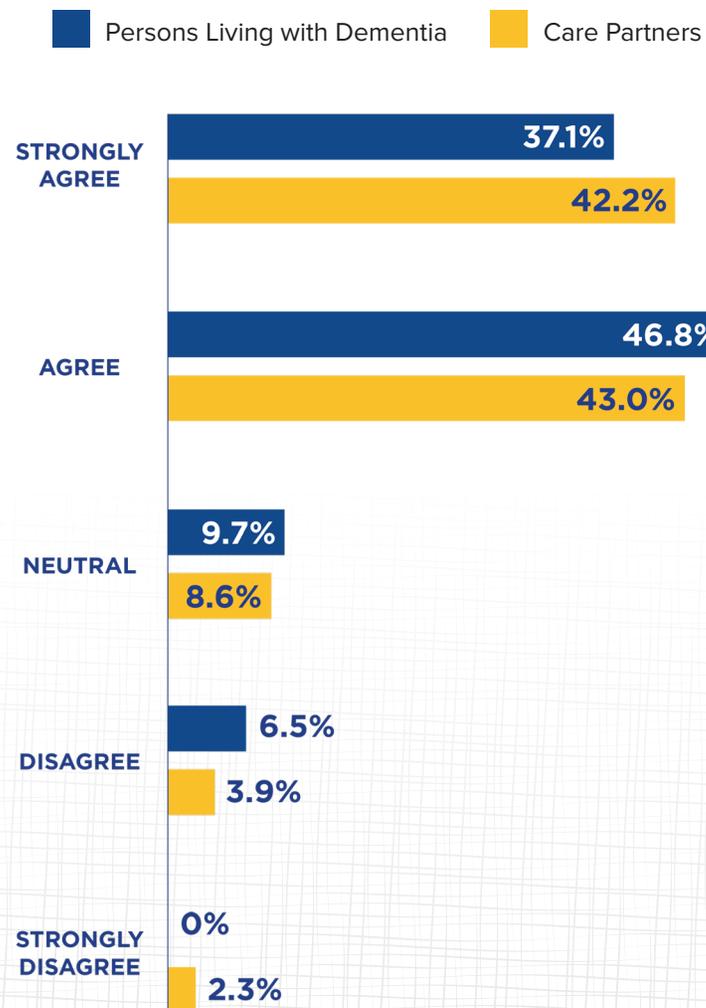
“ I can't tell you how big a burden has been lifted off my shoulders.”
— care partner, spouse

First Link[®] Care Navigation evaluation results

I was connected to supports/services at the time of my need

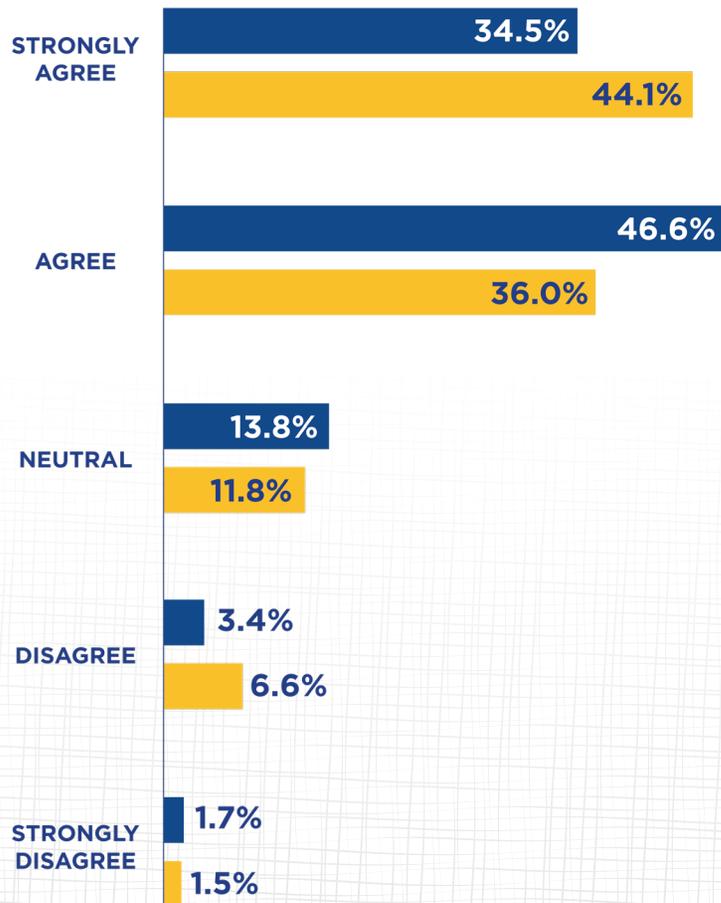


I feel better able to ask or advocate for help with my needs



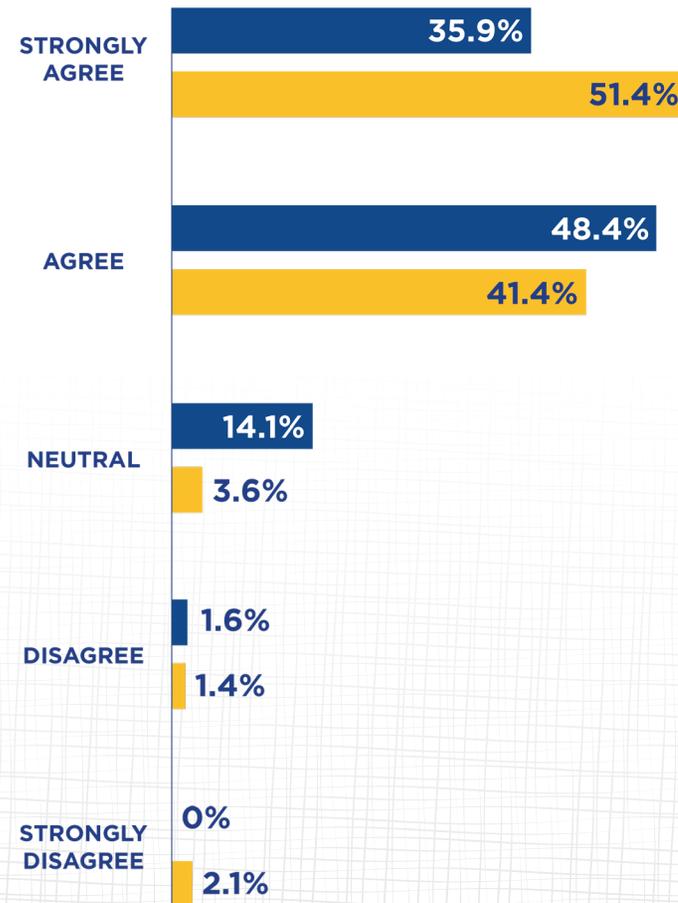
The supports/services that I was connected to met my individual needs

■ Persons Living with Dementia
 ■ Care Partners



The information provided to me by the Alzheimer Society was helpful to me

■ Persons Living with Dementia
 ■ Care Partners





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For more information:

Visit www.firstlinkontario.ca

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