

Your first step to living well with dementia

First Link is an innovative referral program designed for people newly diagnosed with Alzheimer's disease and other dementias and their families. It provides support as early as possible and throughout the progression of the disease.

Early access to ongoing services and support makes a huge difference to people with the disease, their families and caregivers. It increases their knowledge and understanding of dementia. It helps them better cope and plan for the future, improving quality of life. First Link also helps reduce stress and prevent crises.

First Link connects people to:

- A learning series offering information about diagnosis, day-to-day living, positive approaches to care, how to manage challenges and how to prepare for the future
- Support groups and opportunities for one-to-one counselling
- Additional community programs and services

Making a referral is simple

As soon as the diagnosis is made, the health-care professional asks the person with dementia and his or her family for permission to refer them to First Link. Once consent is given, the health-care professional completes a referral form and sends it to the Alzheimer Society First Link team.



Within four weeks, a First Link support counsellor calls the person with dementia or a caregiver to provide information, assess needs, and connect them directly to information and support services in their community. Those diagnosed and their families also can call First Link directly.

Why First Link matters

The diagnosis of dementia can be sudden and frightening, plunging families into a sometimes confusing network of medical care and social services.

People may not know what to do or who to call. Too often families struggle to cope with the challenges alone, waiting until a crisis – an emergency room visit or caregiver burnout – before seeking help.



First Link bridges the gap between diagnosis and support. It offers a single point of entry to appropriate health-care information and referral to other services available locally, such as medications, activity programs, education and life planning. Families learn about, plan for and adjust to dementia.

Earlier interventions allow people with dementia to live independently longer and families to provide care at home as long as possible. Each year one person is delayed from entering long-term care results in a saving of \$50,000.

Making the job easier for health-care professionals

First Link makes the job of primary-care providers easier by allowing them to connect their patient to essential information and support services. Health-care professionals can be confident that people referred to the program will receive the appropriate follow-up services and support earlier and throughout the progression of the disease. Families make better use of their time with physicians because they have more information and support, and may see them less often because of fewer crises.

First Link benefits Ontario's health-care system:

- First Link helps reduce the number of visits to Emergency Departments, days spent in ALC (alternative-level-of-care) beds and crisis-related long-term care placements.
- Earlier interventions allow people with dementia to live independently longer and families to provide care at home as long as possible. Each year one person is delayed from entering long-term care results in a saving of \$50,000.
- First Link strengthens partnerships between the Alzheimer Society and physicians, diagnostic and treatment services, and community service providers.
- The growth of First Link means health-care professionals in Ontario are able to serve more people with dementia.

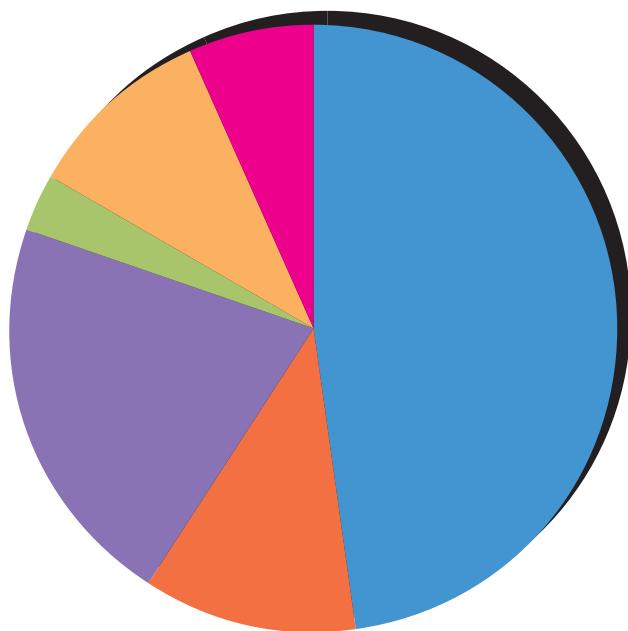
"Caring for patients with dementia is a journey that requires the development of new skills, creation of support systems, compassion and 'outside the box' thinking to provide the best possible care. I believe that First Link has been able to tremendously impact this journey for all of us."

Kerstin Mossman MD, CCFP
Focus Practice in Care of the Elderly
Barrie Community Health Centre

Success in numbers

Since 2007 First Link has grown into a successful service delivery model enthusiastically endorsed by the medical community and based on the *Canadian Consensus Guidelines on Dementia*:

- First Link expanded to 36 Alzheimer Societies in Ontario often with funding from the Ministry of Health and Long-Term Care through Local Health Integrated Networks (LHINs).
- In 2011, more than 20,000 Ontarians used First Link, including more than 15,000 caregivers and 5,000 people with dementia.
- Health-care professionals made over 6,000 referrals to First Link. People referred to the program received support on average 11 months sooner than those without a referral.
- First Link has been nationally recognized and adopted by the Alzheimer Societies of British Columbia, Saskatchewan, Manitoba, Nova Scotia and Prince Edward Island.



Referral sources – 2010-2011

■	Self-directed referral - 5835
■	Primary care referral - 1375
■	Specialized geriatric referral - 2582
■	Acute care referral - 384
■	Community Care Access Centre (CCAC) refer - 1217
■	Community support services referral - 790

Early diagnosis and support helps families live better

Eric Kennedy was a 37-year veteran of Kitchener Hydro when his wife, Gayle Salter-Kennedy, noticed he was having trouble remembering and understanding. His family doctor referred Eric to Dr. Gagan Sarkaria, a geriatrician at St. Mary's General Hospital, who diagnosed him with Frontotemporal dementia (FTD), a degenerative condition of the front part of the brain. He asked the couple if they wanted a referral to the Alzheimer Society's First Link program. They said yes. It was a difficult diagnosis to receive. They didn't know what to expect.

"I knew about the Alzheimer Society but probably wouldn't have called them," Gayle says. "Having them call me right away made it easier. They explained how they can help and what programs are available. Without the Alzheimer Society we would have been lost. I started attending a caregiver support group right away and talked with people who understand because they're going through the same thing." Gayle learned more about dementia and what to expect through a series of First Link education sessions called Next Steps and Care Essentials.

Eric and Gayle also decided to take the Society's Memory Fit program together with three other couples from an early-onset support group. This helped them learn strategies to work around his memory problems and maintain a more normal life. And it's given Eric a chance to get to know other men facing similar challenges. "First Link has been a key piece for us in learning to manage and get on with our lives in a positive way," says Gayle.

"The First Link® education series was especially helpful for my mom to understand what's happening in my dad's brain. We're much more patient with dad and it's helped me to appreciate the time I spend with him. My mom, my sister and I have been going to the First Link support group together for four years and without it we would have been burned out by now. The women share their stories and there are so many similarities with our situation. Mom doesn't feel alone anymore. First Link increased our confidence that we can cope and taught us ways to not sweat the small stuff, so it's better for my dad too."

Carole Legault, Timmins

Quality service, quality of life

Alzheimer Societies in Ontario work together to ensure quality of service to First Link clients and health-care partners.

In 2011, we:

- Developed common information systems to record and report on services provided
- Attended the annual Skills Exchange to learn how to improve service from our health partners and each other
- Created a survey for people with dementia, families and health providers to help us improve what we do
- Examined the effectiveness of our First Link Learning Series

Find out how First Link® can help you. Visit www.alzheimer.ca/on

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