

# FIRST LINK: STRENGTHENING PRIMARY CARE PARTNERSHIPS FOR DEMENTIA SUPPORT

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## ABSTRACT

While primary care faces many challenges, including an increasing prevalence of older individuals, emerging knowledge about the potential benefits of collaborative partnerships has encouraged the development of new means of providing and supporting primary care. First Link™ is an innovative program involving collaborations among primary care providers, Alzheimer Societies, and other health professionals. The program aims to support persons with Alzheimer's and related diseases after the diagnosis is made and to link them with support services earlier in the disease course. This paper describes the First Link program, provides an overview of a study currently underway to evaluate it, and identifies some of the benefits and challenges associated with this partnership.

A convergence of new thinking, pressing issues, and new initiatives across Canada points to the potential of collaborative partnerships between primary care and community services for early diagnosis and subsequent interventions for persons with Alzheimer's and related diseases. Health professionals are recognizing the importance of interdisciplinary care, especially for chronic diseases and higher risk populations, such as the elderly. Concurrently, the demographic pressures of an aging population can no longer be ignored or shuffled off to someone else.

Some governments are responding positively with new initiatives, such as the interdisciplinary Family Health Teams (FHTs) established in Ontario, while the introduction of the chronic disease

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management framework (Wagner, 1998) provides a framework for looking at changes to systems of care to better meet the needs of seniors.

First Link™ is an innovative program that enables primary care providers to provide more comprehensive care to persons with Alzheimer's and related diseases by establishing strong partnerships with Alzheimer Societies. This paper describes the First Link program, reviewing its components in the context of (a) evidence from the literature and (b) recent advances in primary care reform. The paper also provides a brief description of an evaluation of a demonstration project currently underway in Ontario and Saskatchewan.

## LITERATURE REVIEW

The prevalence of dementia is anticipated to escalate over the coming decades. Between 2005 and 2010 the number of people with dementia in Ontario will increase by an estimated 17%, from approximately 150,000 to 175,000; by 2031 an estimated 340,000 people will have dementia, an increase of nearly 55% (Hopkins & Hopkins, 2005). Alzheimer's disease, a progressive, degenerative disease affecting the brain, accounts for approximately 65% of dementias (Lindsay, Sykes, McDowell, Verreault, & Laurin, 2004). Cognitive degeneration associated with Alzheimer's and related diseases is characterized by significant psychological (mood) comorbidity and behavioural disturbances, resulting in dependence in activities of daily living and eventually the need for full-time care (Patterson et al., 1999).

The burden of dementia is felt at various levels including that of the health care system. A 2007 Canadian study identified Alzheimer's and related diseases as having the second highest impact on health care costs among all neurological diseases, second only to strokes (Canadian Institute for Health Information, 2007). The impact is also felt by caregivers. Fifty percent of individuals with dementia reside in their own homes (Canadian Study of Health and Aging Working Group, 1994). Most (97%) live with a caregiver. The majority of caregivers are over 60 years of age; 36% are over 70 years of age (Canadian Study of Health and Aging Working Group, 1994). Family caregivers provide most of the care to individuals with dementia, often with minimal formal support or assistance (Peacock & Forbes, 2003).

Caregivers of individuals with dementia have experienced a decline in physical and mental health (Mittelman et al., 1995; Owen et al., 2002; Schulz & Martire, 2004) and financial stress (George & Gwyther, 1986). Caregiver stress has been identified as a significant predictor of early nursing home placement for the person with dementia (Fisher & Lieberman, 1999). Compared with other chronic conditions, the demands of dementia on caregivers are particularly severe (Clipp & George, 1993; University of Waterloo, 2007). For example, an Ontario Home Care study reported that those providing informal care to persons with dementia are likely to spend 75% more time caregiving than those providing care to individuals with other conditions (University of Waterloo, 2007).

While various community services have been developed to provide support to family caregivers of individuals with dementia, relatively few families access services early in the disease course and many wait until they face a crisis to seek help (Pratt, Clare, & Kirchner, 2006). Lack of awareness of

available support services and the stigma associated with dementia can contribute significantly to the non-use of formal services (Morgan, Semchuk, Stewart, & D'Arcy, 2002).

Access to community-based services early in the disease can help caregivers adjust to the caregiving role and establish supportive, enduring relationships with service providers (Gaugler, Kane, Kane, & Newcomer, 2005). Use of community services and caregiver counselling has been found to delay the institutionalization as well as the death of care recipients (Brodaty, Gresham, & Luscombe, 1997), improve interactions between caregivers and care recipients (Corbeil, Quayhagen, & Quayhagen, 1999), and significantly reduce depressive symptoms in caregivers (Mittelman et al., 1995). In a longitudinal study of the effectiveness of a social work intervention for caregivers, researchers found that intervention group caregivers maintained their loved ones at home significantly longer (an average of 585 days) than caregivers receiving usual care (Mittelman, Ferris, Shulman, Steinberg, & Levin, 1996). With more than 60% of Ontario long-term care residents having dementia and an average length of stay of 1,058 days (Ontario Ministry of Health and Long-Term Care, 2007), this difference is significant.

### **Early Detection and Primary Care Support**

The health care system faces challenges in meeting the needs of individuals with Alzheimer's and related diseases, particularly in primary care settings, which have been described as under-resourced to provide comprehensive management for dementia (Callahan et al., 2006; Sachs, Shega, & Cox-Hayley, 2004). Health care delivery is particularly difficult in rural areas where access to specialists and community supports is limited (Teel, 2004). Care may be further complicated by comorbid conditions frequently experienced by individuals with dementia (Sambrook et al., 2004).

Early detection of dementia provides an opportunity for the individual to adjust to the diagnosis and to participate actively in planning for the future (Woods et al., 2003), which can reduce the heavy societal costs associated with institutionalization (Leifer, 2003). Undetected dementia places older adults at risk for delirium, motor vehicle accidents, medication errors, and financial difficulties (Sternberg, Wolfson, & Baumgarten, 2000).

Although primary care physicians are in an ideal position to diagnose dementia, cognitive impairment is often unrecognized by family physicians (Iliffe & Manthorpe, 2002). Many barriers to recognition have been identified, including lack of time and ability to screen for dementia (Chodosh et al., 2004), lack of knowledge about dementia (Barrett, Haley, Harrell, & Powers, 1997), lack of symptom recognition (Woods et al., 2003), and belief that early detection increases patient and caregiver distress (Iliffe & Manthorpe, 2004).

## **DESCRIPTION OF FIRST LINK**

First Link was developed to address the need to provide individuals with Alzheimer's and related diseases and their caregivers with education and support early in the disease process. The program was founded in Ottawa, where a service partnership was developed between the Alzheimer Society of Ottawa and the health services represented by the Champlain Dementia Network<sup>1</sup> to enable ease of access to community services for persons with dementia and their family caregivers. An evaluation of

Ottawa's First Link program in 2004 reviewed referrals to the program, obtained feedback on education sessions, and assessed satisfaction among clients, physicians, and other health professionals. While the program was rated positively, analysis of the referral data indicated that only 5% of First Link clients were directly referred by their family physician (Alzheimer Society of Ottawa, 2004).

Around the same time, primary care reform in Ontario provided an impetus to modify the First Link program, placing greater emphasis on collaboration with primary care. First, the province introduced Family Health Teams (FHTs) of interdisciplinary professionals to strengthen the prevention and management of chronic disease, including dementia (Ontario Ministry of Health and Long-Term Care, 2005). Second, Ontario's Chronic Disease Prevention and Management (CDPM) model, an extension of Wagner's chronic care model (Wagner, 1998), was promoted as the model of choice to improve chronic disease care. Two aspects of the CDPM model are particularly pertinent to First Link: (a) community action, which speaks to establishing collaborative relationships between the health care sector and community organizations, and (b) support for self-management. Self-management, according to one well-accepted definition, "relates to the tasks that an individual must undertake to live well with one or more chronic condition. These tasks include gaining confidence to deal with medical management, role management and emotional management" (McGowan, 2005, p. 3).

Modification of First Link to place greater emphasis on strong relationships with primary care supports these two areas of reform. Working closely with FHTs enables Alzheimer Societies to link not only with family physicians but also with other members of the primary care team, thereby increasing the likelihood that diagnosed patients and their caregivers will have the opportunity to access information and support earlier in the disease course. First Link is also consistent with the CDPM framework, supporting the development of "informed activated patients" as well as "prepared, proactive" primary care teams (Wagner, 1998).

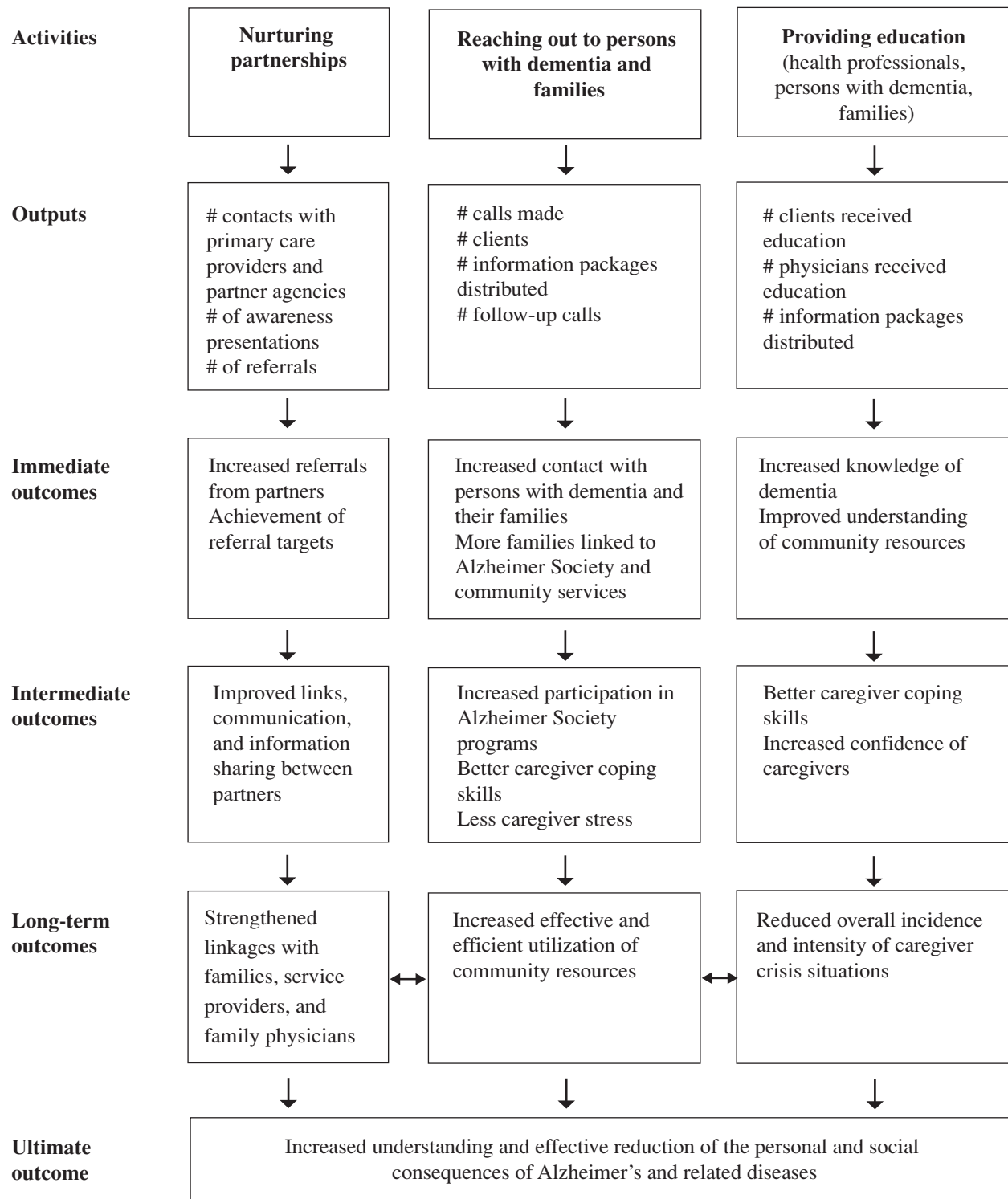
A program logic model of First Link is presented in Figure 1. The specific objectives of the program are to

- enhance linkages between the First Link coordinator and primary care physicians, other health care professionals, and community service providers;
- improve coordination of care and linkages to community services for non-medical management issues;
- increase understanding among primary care physicians and health care professionals of the assessment and management of dementia and the role of community resources; and
- increase understanding among individuals with dementia and their caregivers of dementia and community resources, and thereby increase coping and confidence among caregivers.

### **Enhance Linkages With Health Professionals**

Enhancing linkages with primary care providers and other professionals is essential to the success of First Link. When First Link is introduced into a community, much of the initial work involves marketing the program and education about the referral process. Information is shared with potential referral sources in numerous ways: mailed materials, telephone conversations, and on-site presentations.

**Figure 1**  
**First Link Program Logic Model**



### **Improve Coordination of Care and Linkages to Community Services**

In a typical situation when a person is diagnosed with dementia, the physician (one hopes) suggests to the patient and caregiver that they call the local Alzheimer Society for information and support. Many individuals, however, delay accessing services and seeking help (Pratt and Kirchner, 2006). With First Link, when a diagnosis is made, the physician obtains permission to share the patient and caregiver's contact information with the Alzheimer Society who then contacts them directly. Thus, the onus is on the Alzheimer Society to make the first contact. The First Link coordinator offers information about the disease, services, and education opportunities in the community. After the initial contact, the individual is linked with another staff member in the Alzheimer Chapter for longer term support.

### **Provision of Education and Support**

Education is another key component of First Link. For primary care providers and other health professionals, Alzheimer Society staff may provide education directly or may coordinate educational events (e.g., a session on driving and dementia presented by a local expert). For individuals with dementia and their families, education sessions are offered through the Alzheimer Society as well as other community resources.

The Ontario Ministry of Health and Long-Term Care has funded a demonstration project involving nine Alzheimer Chapters in four geographic areas. Saskatchewan has also secured funding to test-pilot the program. A study of the First Link programs in Ontario and Saskatchewan is currently underway with funding from the Ontario Ministry of Health and Long-Term Care and the Alzheimer Society of Canada.

## **EVALUATION METHODS**

Evaluation of the First Link demonstration project in Ontario and Saskatchewan will (a) examine the utilization of First Link, particularly among primary care providers, (b) assess the program's impact on caregivers and individuals with dementia, (c) assess the program's impact on primary care providers and other health professionals, and (d) describe the implementation of First Link (e.g., facilitators and barriers to implementation, lessons learned, and suggestions for improvement and sustainability).

A mixed method, prospective cohort design is being used to evaluate First Link. Study participants include First Link clients (i.e., caregivers) and persons with dementia, health professionals who have referred clients to the program, and representatives from the demonstration sites. Data sources include (a) First Link referrals and client contacts, (b) surveys of caregivers and health professionals, and (c) interviews and focus groups with key stakeholders, persons with dementia, and caregivers. Evaluation results are anticipated in 2010. Ethics approval for this study has been obtained from the McMaster University Research Ethics Board.



## DISCUSSION

First Link is an innovative collaboration between the Alzheimer Society, primary care providers, and other health professionals that aims to meet the needs of persons with dementia and their caregivers in a more comprehensive fashion, by connecting them to local dementia-specific supports and learning opportunities at the time of diagnosis and throughout the course of the disease. By forging these connections, individuals with dementia and their caregivers have the opportunity to access services earlier in the disease process, which may reduce the number of crises and alleviate caregiver burden.

While the potential benefits of First Link are significant, the move toward such collaborative models has its challenges. Establishing partnerships between community providers and primary care is relatively new ground for both groups. Fortinsky (1998) reported that few community-based interventions for dementia included primary care providers and that this lack of involvement contributed to lower referral rates by physicians to these community support services. More recently, however, examples of such collaborations have begun to emerge (Bass, Clark, Looman, McCarthy, & Eckert, 2003; Béland et al., 2006; Burns, Nichols, Martindale-Adams, Graney, & Lummus, 2003; Cherry et al., 2004; Venohr et al., 2001). Further research on these partnerships can illuminate the factors that contribute to success.

Other collaboration challenges faced by the partners include the lack of time, resources, and experience in working together (van Eyk & Baum, 2002), and the distance between providers (Knight, 2004). Early lessons from the First Link evaluation suggest that while establishing partnerships with primary care providers takes more time than anticipated, referral rates and referral sources are increasing, suggesting that the program is succeeding.

Other examples of primary care partnerships for dementia have been reported in the literature. Some involve the addition of resources to support patients and caregivers (e.g., Bass et al., 2003; Burns et al., 2003; Cherry et al., 2004); others focus on the needs of family members caring for individuals at later stages of the disease, such as how to deal with behavioural challenges (e.g., Burns et al., 2003). However, First Link is unique for a number of reasons. First, the program focuses on crisis prevention by linking with patients and their caregivers earlier in the disease. Second, involvement of the Alzheimer Society with the person with dementia and his or her caregiver is anticipated to be a lifelong commitment. Third, First Link's focus on strengthening collaborations with primary care to enhance services is the first of its kind in Canada. The consistency of the First Link program with the CDPM framework supports the viability of the program on a long-term basis.

First Link also provides an opportunity to explore other ways that community agencies such as the Alzheimer Society can support primary care. Primary care practices are busy places, and patients with dementia can place high demands on time (Tranmer, Croxford, & Coyte, 2003). Some First Link programs have been asked to further assist primary care providers by conducting initial screening of patients, thus enabling providers to focus on persons who require follow-up assessment (e.g., further investigations to confirm a diagnosis of dementia or to determine the type of dementia).

Sustainability of First Link will be an important consideration. Program costs include salary and benefits for a First Link coordinator, marketing materials, and administration (e.g., overhead costs such as supplies, equipment, and administrative support). Based on the Ottawa experience, it is anticipated that a coordinator will receive 400 referrals per year. Alzheimer Society Chapters in areas with smaller populations can share a coordinator across two or three Chapters, thereby reducing costs. In Ontario, long-term funding for the program may be available through government initiatives such as the Aging At Home Strategy.<sup>2</sup> In fact, an additional 15 Alzheimer Chapters received funding to implement First Link in their communities in Year 1 of this strategy.

### SUMMARY

Many providers have recognized that adequate care for complex diseases such as dementia requires a web of disciplines, agencies, family members, and community supports. Yet, there are few models to bridge sectors and professions and to bring coordinated support to persons with Alzheimer's and related diseases, especially in the early stages. The First Link evaluation, accompanied by progressive learning from initiatives such as Family Health Teams in Ontario, will provide valuable insights into how to better serve this growing segment of persons with complex needs.

### NOTES

1. The Champlain (formerly Ottawa) Dementia Network is a network of organizations and individuals who provide care and support to persons with Alzheimer's and related diseases (including the local Alzheimer Societies, long-term care homes, community agencies, family physicians, diagnostic assessment and treatment services, and family caregivers). Their mandate is to improve the coordination and efficiency of clinical care for persons with dementia. (Retrieved June 8, 2008, from <http://www.champlaindementianetwork.org/default.asp>)
2. The goal of Ontario's Aging At Home Strategy is to support initiatives that enable older adults to live healthy and independent lives and to remain in their own homes. (Retrieved June 9, 2008, from <http://www.lhins.on.ca/page.aspx?id=866>)

### RÉSUMÉ

L'émergence de nouvelles connaissances sur les efforts de collaboration, conjuguées aux difficultés liées à la prestation des soins primaires et la pression démographique, ont favorisé le développement de nouveaux moyens de dispenser et d'appuyer les soins primaires. Premier lien<sup>MD</sup> est un programme novateur, fondé sur la collaboration entre les sociétés Alzheimer, les prestataires de soins primaires et d'autres professionnels et professionnelles de santé, qui vise à soutenir les personnes qui reçoivent un diagnostic de maladie d'Alzheimer ou d'affections connexes en les mettant en contact avec les services de soutien plus tôt au cours de la maladie. Cet article décrit le programme Premier lien<sup>MD</sup>, offre un aperçu de l'étude présentement en cours en vue de son évaluation et décrit certains des avantages et des difficultés liés à ce type de partenariat.



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