

# First Link Demonstration Project

## Appendices to the Final Evaluation Report

Submitted to: Alzheimer Society of Ontario

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<sup>1</sup> This is an appendix to: McAiney, C.A., Hillier, L.M., & Stolee, P. (2010) First Link Demonstration Project. Final Evaluation Report. Hamilton, ON: Authors. Available on the Alzheimer Society of Ontario website: [www.alzheimerontario.org](http://www.alzheimerontario.org).

## **APPENDIX A: First Link: The Ottawa Experience**

This First Link Demonstration Project has emerged from a similar pilot project developed by the Alzheimer Society of Ottawa in collaboration with the Dementia Network of Ottawa and implemented from April 2002 to March 2004 with funding from the Ontario Trillium Foundation. In 2001 the Dementia Network of Ottawa identified two gaps in the provision of dementia care in the city of Ottawa. Firstly, many families affected by dementia did not access support services until a crisis situation developed. Secondly, support was lacking for families coping with the end stage of dementia. The First Link program was developed to fill those gaps. Given the anticipated increase in the number of individuals that will be diagnosed with dementia in the upcoming decade and the recognition that one single organization will be unable to adequately support all individuals and families affected by ADRD, a collaborative partnership between teams of physicians, geriatricians, Alzheimer Society staff, social workers, nurses, occupational therapists and others was proposed to provide support to individuals with dementia and their family caregivers.

During the two year pilot project, the First Link program was promoted in a number of ways in order to garner referrals. The First Link Coordinator made presentations to more than 20 partner agencies of the Dementia Network of Ottawa, more than 1000 First Link referral kits were mailed to Ottawa area family physicians, office visits were conducted with more than 70 family physicians, four physicians' dinners were held for more than 100 family physicians, and the program was promoted through the media with articles in local newspapers, television and radio programs.

Referrals to First Link were implemented as the next step after a diagnosis. Families received a call from the First Link Coordinator or First Link Volunteer within 3 – 4 weeks of the referral. The goal of the initial phone call was to build a link between the family and the First Link program. Families were given the opportunity to ask questions about the new diagnosis, offered written information about the disease, informed of community supports as needed, and were encouraged to participate in the First Link learning series (education sessions taught by staff of Dementia Network of Ottawa organizations), a peer support program (peer volunteers that act as mentors to caregivers) and other appropriate supports provided by Dementia Network of Ottawa organizations.

Between April 2002 and March 2004, 699 families were referred to First Link; 92% accepted the referral to First Link and expressed an interest in participating in the services of the program (Alzheimer Society of Ottawa, 2004). Many (42%) participated directly in learning or peer support. Referrals to First Link were made by Dementia Network of Ottawa partners (70%), Family Support and Education staff of the Alzheimer Society (17%), family physicians (5%) and by family members (17%, either on their own or as advised by a physician).

Evaluation of the Ottawa experience included surveys completed by family members participating in First Link, referring physicians, and other health care providers. Evaluation results indicated that First Link has helped individuals with dementia and their family members

in several ways, including: learning more about ADRD, linking families to community services, increasing caregivers' confidence in caring for their family member, and helping caregivers to more effectively manage crises (Alzheimer Society of Ottawa, 2004). The First Link program also had benefits for community agency staff and family physicians. Health care professionals reported that they had a stronger relationship with the Alzheimer Society as a result of the First Link program. Family physicians reported that their patients greatly benefited from First Link. The primary reasons why physicians and health care professionals referred families to First Link were for education, support and information. These reasons support the project's goal of ensuring that individuals with dementia and their families have early access to learning, services and support.

The First Link Demonstration Project described here is based on the Ottawa experience. However, this project differs in that there is greater emphasis on partnering with primary care providers, in particular, family physicians and allied health professionals within FHTs and CHCs.

## **APPENDIX B: Selection Criteria for the Demonstration Sites**

The Alzheimer Society of Ontario developed the following criteria for demonstration site selection:

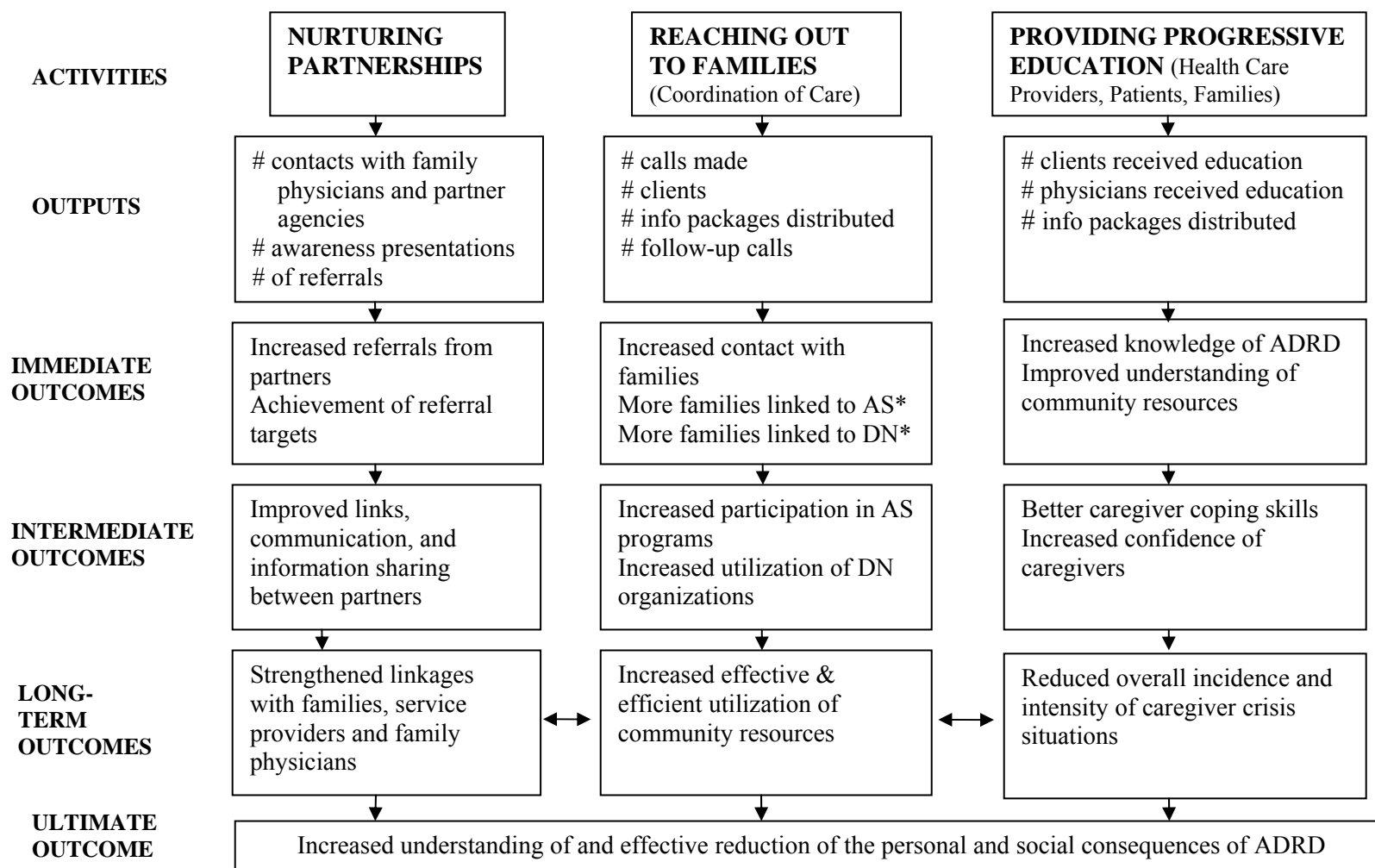
- the Chapter has distinguished itself as a leader in the community;
- the Chapter has identified how the community will benefit in being involved in First Link;
- the Chapter participates as a full member in the Dementia Network;
- the Chapter has an understanding of Family Health Teams/Chronic Disease Framework;
- the Chapter is currently reaching out to primary care practitioners;
- the Chapter has at least one 'primary care reform' partner committed to the project;
- the Chapter reflects a target community, e.g. small, large, urban, rural, mix;
- the Chapter will adhere to standards/project model outlined in First Link initiative;
- the Chapter is willing and able to accommodate temporary staff at no additional cost; and,
- the Chapter has the capacity to provide administrative support to First Link Coordinator.

## APPENDIX C: Profiles of The Demonstration Sites

Services	Ottawa	Kingston			Grey Bruce/Huron/Perth			Sudbury/Timmins	
		Kingston	Belleville	Prince Edward	Grey Bruce	Huron	Perth	Sudbury	Timmons
Information and referral	●	●	●	●	●	●	●	●	●
Support groups for caregivers	●	●	●	●	●	●	●	●	●
Support groups for individuals with dementia	●	●	●	●	●	●	●	●	
Individual support and information	●	●	●	●	●	●	●	●	●
Volunteer visiting				●		●	●		
Walking				●		●	●		
In Home respite								●	
Day Away/ Day Centre								●	
Education/ Training	●	●	●	●	●	●	●	●	●
Public Education/ Awareness	●	●	●	●	●	●	●	●	●

Services	Ottawa	Kingston			Grey Bruce/Huron/Perth			Sudbury/Timmins	
		Kingston	Belleville	Prince Edward	Grey Bruce	Huron	Perth	Sudbury	Timmons
Intergenerational programming	•	•					•		•
RememberME				•				•	
Advanced Care Planning	•	•	•	•	•	•	•	•	•
Enhancing care	•	•	•	•	•	•	•	•	•
Library	•	•	•	•	•	•	•	•	•
Art Therapy		•							
Music Therapy			•		•				
Safety/ Home/ Alarms							•		•

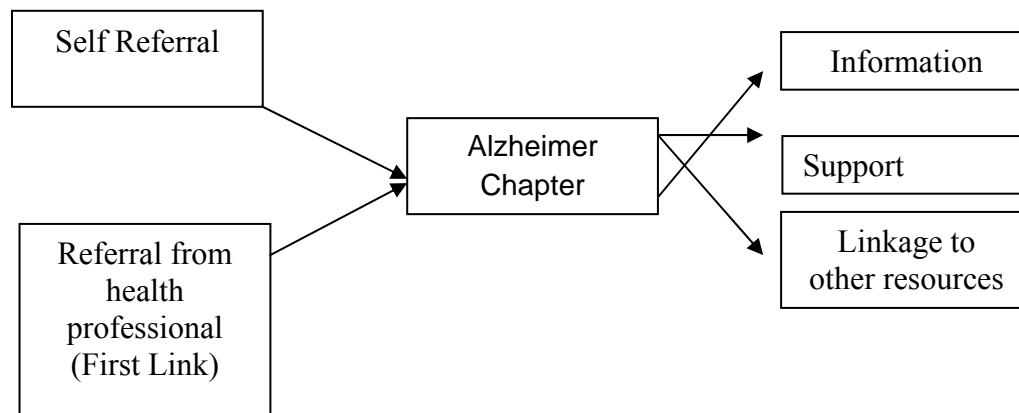
## APPENDIX D: First Link Project Logic Model



\* ADRD – Alzheimer Disease and related dementias; AS = Alzheimer Society; DN = Dementia Network



## APPENDIX E: First Link Referral Process



## APPENDIX F: First Link Demonstration Project Evaluation Framework

Objective	Indicators	Measures	Sources of Information
<p>1. To enhance linkages between the AS and:</p> <ul style="list-style-type: none"> <li>• diagnosing primary care physicians</li> <li>• diagnostic and treatment services, and</li> <li>• community service providers.</li> </ul>	<ul style="list-style-type: none"> <li>• Increased referrals from partners.</li> <li>• Improved communication and information sharing between partners.</li> <li>• Increased links with Family Health Teams (FHTs) and Community Health Centres (CHCs).</li> </ul>	<ul style="list-style-type: none"> <li>• AS tracking of referrals (First Link Records) pre-post (separate tracking for FHTs, anticipating their referrals may be higher).</li> <li>• Referral information as assessed through information systems or electronic patient records maintained by FHTs.</li> </ul>	<p>First Link Referral Tracking</p> <p>First Link Client Tracking</p> <p>First Link Information and Awareness Raising Activities Recording form</p> <p>Survey of Primary Care Providers</p> <p>Interviews with Key Stakeholders</p>
<p>2. To increase understanding and awareness, among family physicians and allied health professionals of:</p> <ul style="list-style-type: none"> <li>• assessment and management of dementia</li> <li>• role of the Alzheimer Society (AS) and the First Link program, and</li> <li>• other community resources for individuals with</li> </ul>	<ul style="list-style-type: none"> <li>• Increased knowledge and understanding of AD/dementia.</li> <li>• Improved understanding of available community resources.</li> </ul>	<ul style="list-style-type: none"> <li>• Process measure: number of information packages/ referral kits sent to physicians and allied health professionals.</li> <li>• Process measure: number of First Link presentations and attendance.</li> </ul>	<p>First Link Information and Awareness Raising Activities Recording form</p> <p>Survey of Primary Care Providers</p> <p>AS Chapter referral tracking</p>

dementia and/or their caregivers.		<ul style="list-style-type: none"> <li>• Self-reported awareness and use of decision tools / best. practice guidelines.</li> <li>• Perception of relationship between FL and primary care providers</li> </ul>	
<p>3. To increase understanding and awareness, among individuals with dementia and family members/caregivers, of:</p> <ul style="list-style-type: none"> <li>• knowledge and understanding of AD/dementia,</li> <li>• understanding of community resources,</li> <li>• coping and confidence of caregivers, and</li> <li>• self-efficacy for self-management.</li> </ul>	<ul style="list-style-type: none"> <li>• Number of calls / information packages to individuals and families.</li> <li>• Number of clients and family members receiving education.</li> <li>• Increased knowledge and understanding of AD/dementia,</li> <li>• Improved understanding of community resources,</li> <li>• Enhanced coping and confidence of caregivers, and</li> <li>• Increased self-efficacy for self-management.</li> </ul>	<ul style="list-style-type: none"> <li>• Tracking of calls and information packages distributed to individuals referred through First Link.</li> <li>• Tracking First Link individuals and family members' participation in education sessions.</li> <li>• Self-reported measures of knowledge, understanding, coping, confidence and self-efficacy, as appropriate</li> </ul>	<p>Survey of First Link clients and their family caregivers</p> <p>Interviews with a purposeful sample of First Link clients and their family caregivers</p> <p>First Link Client Tracking Form</p> <p>First Link Information and Awareness Raising Activities Recording form</p>
4. To improve coordination of care and linkages to community services for non-medical management issues from time	<ul style="list-style-type: none"> <li>• Increased referrals to AS.</li> <li>• Increased number of participants in AS programs.</li> </ul>	<ul style="list-style-type: none"> <li>• Process measure: number of calls for follow-up and monitoring.</li> </ul>	<p>First Link Referral Tracking Form</p> <p>First Link Client Tracking Form</p>

<p>of diagnosis through the duration of the disease:</p> <ul style="list-style-type: none"> <li>• more families linked to AS,</li> <li>• increased participation in AS programs, and</li> <li>• increased utilization of DN programs.</li> </ul>	<ul style="list-style-type: none"> <li>• Increased referrals to/ contacts with Dementia Network organizations.</li> </ul>		<p>First Link Information and Awareness Raising Activities Recording form</p> <p>Interviews with key stakeholders</p> <p>Individual and Focus Group Interviews with demonstration site coordinators (First Link coordinator, project leaders, and coordinators from each demonstration site)</p>
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## APPENDIX G: Referral and Service Tracking Data

### CLIENT RELATED INFORMATION

#### NEW REFERRALS

##### Primary Caregiver Information

- Caregiver name
- Address (street, city, postal code; if different from client)
- Does the primary caregiver live with the client? (yes, no)
- Home Telephone Number
- Gender
  - ☐ male
  - ☐ female
- Date of Birth (month/year)
- Preferred language
- Relationship to client
  - ☐ spouse/partner
  - ☐ child
  - ☐ other family member (relative)
  - ☐ other (non-relative)

##### Client Contact Information

- Name
- Address (street, city, postal code)
- Home Telephone Number
- Gender
  - ☐ male
  - ☐ female
- Date of Birth (month/year)
- Preferred language (English as the default)
  - ☐ French
  - ☐ Other, specify
- Do you live alone?
  - ☐ Yes
  - No

##### Self -Referral Information<sup>2</sup>

- Was this a self referral? ☐ No ☐ Yes

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<sup>2</sup> Coordinators will need to check their records to see if this person had been contacted by FL before and perhaps declined or deferred services.

- Is an indirect referral?<sup>3</sup> ☐ No ☐ Yes
- If yes: How did they hear about First Link?<sup>4</sup>
  - ☐ ASO chapter
  - ☐ Media (print/television/radio)
  - ☐ Participation in an education session
  - ☐ Public awareness session/presentation
  - ☐ Heard about it from a friend/family member
  - ☐ Other (specify)

## Health Information

- Date of diagnosis (month/year)
- Who made the diagnosis?
  - ☐ Family Physician
  - ☐ Specialist (neurologist, geriatrician, geriatric psychiatrist, etc)
- Family physician
  - ☐ Name
  - ☐ Phone number
  - ☐ Does not have a family physician

## Services

- Are any services currently in place?
  - ☐ Alzheimer Society Chapter (specify)
  - ☐ CCAC (specify)
  - ☐ Community Services (specify)
  - ☐ Community Home Support (specify)
  - ☐ Veteran's Affairs (specify)
  - ☐ Community Services (specify)
  - ☐ Other (specify)

## REFERRAL INFORMATION

### Referral Sources

- Source/Organization and discipline/role
  - Primary care:
    - ☐ Family Health Team
      - ☐ Family Physician / General Practitioner
      - ☐ Allied Health Professional<sup>5</sup>

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<sup>3</sup> Indirect referral – the client was instructed by health care provider to contact First Link; as opposed to a self-referral where client independently contacts First Link.

<sup>4</sup> Cross reference with incoming referrals from health care providers to determine if there is a referral for this client.

<sup>5</sup> Allied Health Professionals include: nurses, NPs, Mental Health Counsellors

- ☐ CHC:
  - ☐ General Practitioners
  - ☐ Other allied health
  - ☐ Family Physician/General Practitioner (not in a FHT or CHC)
- ☐ Specialist (e.g., neurologist, geriatrician, geriatric psychiatrist)<sup>6</sup>
- ☐ CCAC
- ☐ Include Partner List for each demonstration site (partners not already identified)
- Name of person referring
- Phone number

#### **Client Information:**

- Name
- Address
- Phone number
- Diagnosis
  - ☐ Alzheimer Disease
  - ☐ Frontotemporal dementia
  - ☐ Mixed dementia (vascular & AD)
  - ☐ Vascular dementia
  - ☐ Lewy-body dementia
  - ☐ Parkinson's dementia
  - ☐ Other (specify)
  - ☐ Not yet diagnosed
- Date of diagnosis
- Comments

#### **Referral Date**

- Date on faxed referral form
- Date fax received by First Link staff (business day)<sup>7</sup>

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<sup>6</sup> Need to determine whether to record affiliation (e.g., memory clinic)

<sup>7</sup> This is not the date the fax was transmitted, but the first business day the fax was picked up by First Link staff.

## APPENDIX H: First Link Information And Awareness Raising Activities Tracking

### First Link Awareness Raising Activities<sup>8</sup>

- date
- description of presentation
- purpose
  - ☐ potential referral source
  - ☐ general public awareness
- presenter<sup>9</sup>
- audience
  - ☐ general public
  - ☐ clients/caregivers
  - ☐ physicians
  - ☐ allied health professionals
- type of presentation<sup>10</sup>
  - ☐ rounds/lecture
  - ☐ launch
  - ☐ PowerPoint
  - ☐ Health fair
  - ☐ e-learning
  - ☐ other<sup>11</sup>
- number in attendance

### Education Events<sup>12</sup>

- description of presentation
- presenter
- audience<sup>13</sup>
  - ☐ general public
  - ☐ clients/caregivers
  - ☐ physicians
  - ☐ allied health professionals
- type of presentation<sup>14</sup>
  - ☐ PowerPoint

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<sup>8</sup> Presentations aimed at raising awareness of First Link (purpose, objectives, services offered, referral information)

<sup>9</sup> Need to identify who this might be (FL coordinator, Alzheimer Society staff??)

<sup>10</sup> Coordinators will need to assist in defining what these are.

<sup>11</sup> Other options: Newspaper, radio/TV, newsletters (don't need to determine number in attendance). Opportunities may exist through the AKE to access technology-based forums (e.g., e-learning, Fireside Chats, etc)

<sup>12</sup> Education regarding early diagnosis, management, community resources.

<sup>13</sup> Sign-in sheets should be used for all presentations. Information should include, as applicable: Name, organization, role/discipline

<sup>14</sup> Coordinators will need to assist in defining what these are.



- ☐ rounds
- ☐ e-learning
- ☐ other
- number in attendance

### **First Link Products**

- Number of First Link information packages distributed
- Recipients of First Link information packages
  - ☐ Clients
  - ☐ Caregivers
  - ☐ Healthcare providers
  - ☐ Other
- Number of referral kits distributed
- Recipients of referral kits
  - ☐ Family Physicians/General Practitioners
  - ☐ Family Health Teams
  - ☐ Community Health Centres
  - ☐ Specialists
  - ☐ Other
- Number of media kits distributed
- Number of articles generated (print/radio/tv)

## APPENDIX I: Baseline Caregiver Survey

When completing this questionnaire please focus on the impact that the diagnosis of Alzheimer disease or a related dementia has on your role as a caregiver to the care-receiver (that is, the person with the disease for whom you are caring). If you are the caregiver for someone who has not been diagnosed with Alzheimer Disease or a related dementia, but who may be experiencing memory and/or other symptoms please complete the survey according to your own experience as a caregiver to this individual.

### HEALTH INFORMATION

1. Please select the one statement that best describes the person you are caring for:
  - ☐ This person has been formally diagnosed with Alzheimer Disease or a related dementia
  - ☐ This person has not been diagnosed with Alzheimer Disease or a related dementia, but has experienced memory loss or other similar symptoms.
2. Does the person you are caring for who has been diagnosed with Alzheimer disease or a related dementia have any of the following conditions? Please check all that apply.
  - ☐ arthritis/osteoarthritis
  - ☐ osteoporosis
  - ☐ cancer
  - ☐ heart attack, angina (cardiovascular disease)
  - ☐ diabetes
  - ☐ high blood pressure, stroke (cerebrovascular disease)
  - ☐ depression
  - ☐ psychosis or personality disorder (other psychiatric disorders)
  - ☐ COPD, emphysema, asthma (respiratory diseases)
  - ☐ problems with drugs or alcohol
  - ☐ other – Please specify: \_\_\_\_\_
3. Overall, how would you rate the physical health of the person you are caring for? Please select the one word that best describes how you would rate your care-receiver's health.

Poor	Fair	Good	Very Good	Excellent
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4. How knowledgeable are you about the diagnosis (Alzheimer Disease or a related dementia) that the person you are caring for has?

5. How familiar are you with the community resources related to dementia that are available to you and your care-receiver?

6. Please read each of the following statements and select the one response that best represents how much you agree or disagree with each statement.

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Draft Evaluation Report, April 2010  
McAiney, Hillier & Stolee***



**Caregiver Burden Inventory (included in an initial version of the baseline survey)**

<i><b>Caregiver Burden Scale</b></i>	<b>Not at all 0</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>Very descriptive 4</b>
My care-receiver needs my help to perform many daily tasks.	0	1	2	3	4
My care-receiver is dependent on me.	0	1	2	3	4
I have to watch my care-receiver constantly.	0	1	2	3	4
I have to help my care-receiver with many basic functions.	0	1	2	3	4
I don't have a minute's break from my caregiving chores.	0	1	2	3	4
I feel that I am missing out on life.	0	1	2	3	4
I wish I could escape from this situation.	0	1	2	3	4
My social life has suffered.	0	1	2	3	4
I feel emotionally drained due to caring for my care-receiver.	0	1	2	3	4
I expected that things would be different at this point in my life.	0	1	2	3	4
I'm not getting enough sleep.	0	1	2	3	4
My health has suffered.	0	1	2	3	4
Caregiving has made me physically sick.	0	1	2	3	4

<b>Caregiver Burden Scale</b>	<b>Not at all 0</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>Very descriptive 4</b>
I am physically tired.	0	1	2	3	4
I don't get along with other family members as well as I used to.	0	1	2	3	4
My caregiving efforts aren't appreciated by others in my family.	0	1	2	3	4
I've had problems with my marriage.	0	1	2	3	4
I don't do as good a job at work as I used to.	0	1	2	3	4
I feel resentful of other relatives who could but do not help.	0	1	2	3	4
I feel embarrassed by my care-receiver's behaviour.	0	1	2	3	4
I feel ashamed of my care-receiver.	0	1	2	3	4
I resent my care-receiver.	0	1	2	3	4
I feel uncomfortable when I have friends over.	0	1	2	3	4
I feel angry about my interactions with my care-receiver.	0	1	2	3	4

**First Link Demonstration Project  
Caregiver Study**

**CONTACT INFORMATION**

**The following information is requested so that we can send you the follow-up questionnaires.**

**Name:** \_\_\_\_\_

**Address:** \_\_\_\_\_ **Apt/Suite:** \_\_\_\_\_

**City:** \_\_\_\_\_

**Province:** \_\_\_\_\_

**Postal Code:** \_\_\_\_\_

**Year of Birth:** \_\_\_\_\_

## APPENDIX J: Follow-Up Caregiver Survey

When completing this questionnaire please focus on the impact that the diagnosis of Alzheimer disease or a related dementia has on your role as a caregiver. If you are the caregiver for someone who has not been diagnosed with Alzheimer Disease or a related dementia, but who may be experiencing memory loss and/or similar symptoms please complete the survey according to your own experience as a caregiver to this individual.

### HEALTH INFORMATION

1. Has the person you are caring for been diagnosed with any of the following conditions in the past six (6) months? Please check all that apply.

- ☐ arthritis/osteoarthritis
- ☐ osteoporosis
- ☐ cancer
- ☐ heart attack, angina (cardiovascular disease)
- ☐ diabetes
- ☐ high blood pressure, stroke (cerebrovascular disease)
- ☐ depression
- ☐ psychosis or personality disorder (other psychiatric disorders)
- ☐ COPD, emphysema, asthma (respiratory diseases)
- ☐ problems with drugs or alcohol
- ☐ other – Please specify: \_\_\_\_\_

2. Overall, how would you rate your care-receiver's health compared to when he/she was first diagnosed with dementia?

1	2	3	4	5
Much worse		About the		Much better
now		same		now

### GENERAL INFORMATION

3. How would you rate your current level of knowledge about Alzheimer disease or other dementias compared to your level of knowledge when your care-receiver was first diagnosed with dementia?

1	2	3	4	5
Less		About the		More
knowledgeable		same		knowledgeable
now				now



4. How would you rate your current level of familiarity with community resources that are available to you and your care-receiver compared to your familiarity when your care-receiver was first diagnosed?

1                      2                      3                      4                      5  
 Less familiar                      About the                      More familiar  
 now                      same                      now

5. Please read each of the following statements and select the one response that best represents how much you agree or disagree with each statement.

	<b>Strongly Disagree 1</b>	<b>Disagree 2</b>	<b>Neutral 3</b>	<b>Agree 4</b>	<b>Strongly Agree 5</b>
This illness upsets me as much now as it ever did; I haven't really got used to it.	1	2	3	4	5
The ways I try to cope with this illness are not working too well these days.	1	2	3	4	5
I question whether I'm handling this illness as well as I could.	1	2	3	4	5
The things I do to handle this illness take a lot out of me physically.	1	2	3	4	5
I don't have any control over this illness.	1	2	3	4	5
I can find more or different ways of trying to cope with this illness.	1	2	3	4	5
I'm dealing with this illness better now than I used to.	1	2	3	4	5

6. Overall, how would you rate your current level of confidence in your ability to manage your role as a caregiver to this individual compared to when your care-receiver was first diagnosed?

1                      2                      3                      4                      5  
 Less                      About the                      More confident  
 confident                      same                      now  
 now

7. Overall, how would you rate your current ability to manage your role as a caregiver to this individual compared to your level of ability when your care-receiver was first diagnosed?

1	2	3	4	5
Less capable now		About the same		More capable now

8. Overall, how stressed do you feel by this individual's care (i.e., stress due to time, energy, demands or behaviours)?

1	2	3	4	5	6
No stress at all					The most stress I've ever experienced related to this person

## FIRST LINK

We are interested in learning more about your involvement with the Alzheimer Society's First Link program and how helpful this has been to you.

9. In the past six months have you received any written material about Alzheimer disease and related dementias from First Link or your local Alzheimer Society chapter?

- ☐ No
- ☐ I don't recall
- ☐ Yes – if yes, how helpful was this information to you?

1	2	3	4	5
Not at all helpful				Extremely helpful

10. In the past six months did First Link or your local Alzheimer Society Chapter tell you about or send you information about community resources or services that are available to you?

- ☐ No – I was not given any information about this.
- ☐ No – I received information about this, but I did not contact them.
- ☐ I don't recall
- ☐ Yes - if yes,

How helpful were these resources or services?

1	2	3	4	5
Not at all helpful				Extremely helpful

11. In the past six months did First Link or your local Alzheimer Society Chapter tell you about or send you information about education or information sessions about Alzheimer disease and related dementias?

- ☐ No – I was not given any information about this.
- ☐ No – I received information about this, but I did not contact them.
- ☐ I don't recall
- ☐ Yes - How helpful were these sessions?

1	2	3	4	5
Not at all helpful				Extremely helpful

12. Overall, how satisfied are you with the assistance you have received to date from First Link or you local Alzheimer Society Chapter?

1	2	3	4	5
Not at all satisfied				Extremely satisfied

13. Do you have any comments you would like to make about First Link or you local Alzheimer Society chapter?

## APPENDIX K: First Link Health Professional Survey

We are interested in learning more about your involvement with the Alzheimer Society's First Link program and how helpful this has been to you.

1. In the past year have you received any written material about Alzheimer disease and related dementias from First Link or your local Alzheimer Society chapter?

- ☐ No  
☐ I don't recall  
☐ Yes – if yes, how helpful was this information to you?

1	2	3	4	5
Not at all helpful				Extremely helpful

2. In the past year have you received any information about community resources or services that are available to your patients with dementia from First Link or your local Alzheimer Society Chapter?

- ☐ No  
☐ I don't recall  
☐ Yes - if yes, How helpful was this information?

1	2	3	4	5
Not at all helpful				Extremely helpful

3. Please identify one or two things that you learned about Alzheimer Disease and related dementias (e.g., related to assessment, diagnosis, best practices, available community resources) as a result of your involvement with First Link or your local Alzheimer Society Chapter that you have found particularly useful.

### PRACTICE RELATED TO DEMENTIA CARE

4. To what extent has First Link had an impact on increasing the number of patients diagnosed with Alzheimer Disease and related dementias in your practice / organization?

1	2	3	4	5
Not at all				A great deal

a. Do you have any comments that you would like to make about this?

5. How familiar are you with services and supports provided by the Alzheimer Society (e.g., First Link, support groups, information sessions) in your community?

1	2	3	4	5
Not at all familiar				Extremely familiar

6. How often do you refer patients to First Link and/or the Alzheimer Society?
- ☐ Not applicable (It is not my role to refer patients to these types of services)
  - ☐ With none or hardly any of my patients with dementia
  - ☐ With a few of my patients with dementia
  - ☐ With most of my patients with dementia
  - ☐ With all of my patients with dementia

7. Do you think that the number of patients you refer to the Alzheimer Society has changed as a result of First Link?

1	2	3	4	5
Now referring less		Referring the same		Now referring more

8. How familiar are you with the community support services (e.g., respite care, home help, home safety systems) for Alzheimer Disease and related dementias that are available in your community?

1	2	3	4	5
Not at all familiar				Extremely familiar

9. How often do you refer patients for these community support services?

- ☐ Not applicable (It is not my role to refer patients to these types of services)
- ☐ With none or hardly any of my patients with dementia
- ☐ With a few of my patients with dementia
- ☐ With most of my patients with dementia
- ☐ With all of my patients with dementia

- |                    |   |                       |   |                       |
|--------------------|---|-----------------------|---|-----------------------|
| 1                  | 2 | 3                     | 4 | 5                     |
| Now referring less |   | Referring<br>the same |   | Now referring<br>more |

13. How would you rate your current level of understanding of the supports and services available to those with dementia as a result of First Link?

<i>Level of understanding about...</i>	<b>1 Understand less</b>	<b>2</b>	<b>3 The same</b>	<b>4</b>	<b>5 Understand more</b>
Role of the Alzheimer Society	1	2	3	4	5
Available community resources	1	2	3	4	5

14. Overall, how satisfied are you with the services provided by First Link?

1                      2                      3                      4                      5  
 Not at all                                                                                                          Extremely  
 satisfied                                                                                                          satisfied

## DEMOGRAPHIC INFORMATION

15. What is your discipline?

- ☐ Family Physician/ General Practitioner
- ☐ Specialist: neurologist, geriatrician, geriatric psychiatrist
- ☐ Allied health professional: Registered Nurse, Nurse Practitioner, Mental Health Counsellor
- ☐ Other, please specify:

16. Where do you work? Please select the one response choice that best describes where you practice.

- ☐ Family Health Team (FHT)
- ☐ Community Health Centre (CHC)
- ☐ Primary health care in settings other than FHTs and CHCs
- ☐ Community Care Access Centre
- ☐ Specialized Clinics / Care Teams (e.g., geriatric medicine, geriatric psychiatry)
- ☐ Other, please specify: \_\_\_\_\_

17. What percentage of the individuals in your practice/organization would you estimate are over 65 years of age? \_\_\_\_%
18. What percentage of the individuals in your practice/organization would you estimate have Alzheimer Disease or a related dementia? \_\_\_\_%
19. With which First Link site are associated?
- ☐ Timmins
  - ☐ Sudbury
  - ☐ Kingston
  - ☐ Ottawa
  - ☐ Grey Bruce/ Huron/ Perth
20. Do you have any additional comments you would like to make about First Link or the Alzheimer Society?



## **APPENDIX L: Guide For Interviews With Key Stakeholders**

### **Involvement with First Link**

I'd like to start this interview by asking you about your involvement with First Link.

When did you first connect with First Link and how did this happen (prompts: how did you find out about First Link? Did you approach First Link or did they approach you?)

What kinds of activities have you been involved in related to First Link? (Prompts: Have you referred patients to First Link? Attended or lead education or information sessions sponsored by First Link?)

Can you tell me about your referrals to First Link? In terms of:

- how often you refer patients
- the types of patients you refer
- when you refer them
- the circumstances/conditions under which you refer them, and
- patients receptiveness to be referred to First Link.

Can you tell me about your experience accessing First Link and the services offered?

Prompts:

- How easy or difficult is it to access First Link?
- How easy or difficult is communication with First Link?
- How easy or difficult is to share information with First Link?

### **Perceptions of First Link**

What do you think about the role of First Link, in terms of its aim to provide resources and supports to persons with dementia and their caregivers early in the disease process?

As a service provider, has First Link/ the Alzheimer Society assisted you to better serve patients with dementia and their caregivers? In what ways? How you have benefited from First Link?

Prompts: Impacts/outcomes related to:

- access to information
- earlier identification
- earlier intervention
- ability to address the multiple needs (social support, emotional) of patients and caregivers
- new linkages
- collaborative relationships/partnerships

Can you provide an example based on your experience to illustrate a key impact of this program?

Can you tell me what impacts First Link has had within the health care system, such as the use of health system resources?

Prompts:

- Crises among persons with dementia and/or their caregivers
- Use of emergency departments
- Placement in LTC

What feedback have you heard from your patients/clients or their caregivers about First Link?

### **Suggestions for Improvement**

Do you have any suggestions for improving the services offered by First Link?

Are there any resources or supports that your patients with dementia and their caregivers do not currently have access to, but that you think would improve their quality of life and/or quality of care?

**Additional Comments:** Do you have any additional comments you would like to make about First Link?

## **APPENDIX M: Guide For Interviews With Demonstration Site Representatives**

### **Development and Implementation**

I'd like to start the interview by talking about the development and implementation of the First Link Program.

What worked well with the development and implementation of First Link? What are some of the things that facilitated its development and implementation (e.g., champions, support, interest) locally? Province wide?

What were some of the challenges you faced in developing and implementing First Link? What were some of the factors that hindered optimal implementation? (System, organizational, personal barriers)

- Do you have any suggestions or strategies for overcoming these challenges/barriers?

Were any of the goals/objectives that you had for First Link not achieved?

- What prevented this goal from being achieved?
- What needs to happen/be in place for this goal to be achieved?

### **Lessons Learned/ Generalizability**

What were some of the key lessons you learned in developing and implementing First Link in terms of:

- working with primary care providers
- working with other staff in your chapter
- working with staff in other chapters
- marketing
- meeting your key objectives

What suggestions do you have for improving or sustaining this program?

- Are there any specific resources/ supports needed for successful spread of the program?

What are your future goals or objectives for First Link (Next steps)

- What do you need, or what do you think needs to be place for these goals to be achieved?

Do you think that First Link could be adapted for use in other regions (province/country)?

- Are there any aspects of the program that need to be modified for use in other regions?
- What advice would you have for other regions that are interested in developing a First Link Program?

Can you comment on the value of developing:

- standardized client service record
- standardized program model
- standardized learning series
- counselling services

## **Impact**

What impacts did this program have?

Prompts: What impact did this program have on:

- Access to information about ADRD – for persons with dementia, caregivers, health professionals
- Access to information support services – for persons with dementia, caregivers, health professionals
- Access to services for persons with dementia and caregivers
- Linkages between health professions and community supports/Alzheimer Society
- Early identification of dementia
- Early intervention
- Crises among persons with dementia and/or their caregivers
- Use of emergency departments
- Placement in LTC
- Are there any other impacts we haven't discussed?

Can you provide an example based on your experience to illustrate a key impact of this program?

## **Additional Comments**

Do you have any additional/final comments you'd like to make about the program?

## **APPENDIX N: Guide for Interviews With Caregiver/ Individuals With Dementia Dyads**

### **Involvement with First Link**

I'd like to start this interview by asking you about your involvement with First Link.

When did you first connect with First Link and how did this happen (prompts: how did you find out about First Link? Did you approach First Link or did they approach you?)

What kinds of activities have you been involved in related to First Link?

Prompts:

- Did you receive any information about ADRD from First Link? If yes, how helpful was this information?
- Did you attend any information or education sessions recommended by First Link? If yes, how helpful was this? If no, were any recommended to you? Why did you choose not to attend?
- Did First Link recommend any community services or supports? If yes, did you contact these services? How helpful was this? If not, why did you choose not to contact these services?

### **Perceptions of First Link**

Can you tell me about your experience accessing First Link and the services offered?

Prompts

- How receptive were you to being referred to First Link?
- How easy or difficult was communication with First Link?

First Link aims to provide resources and supports to persons with dementia and their caregivers early in the disease process – soon after the diagnosis. What do you think of this? Do you think this is helpful for persons with dementia and their caregivers?

What has been the impact of your relationship with First Link and the Alzheimer Society? Can you tell me about how you have benefited from First Link?

Prompts: Impacts/outcomes related to:

- Access to information/education
- Information about support services
- Linkages to other resources
- Caregiver stress
- Caregiver coping
- Use of health care services such as emergency departments

Overall, what how satisfied are you with First Link (prompt for explanations – what/why are they satisfied/dissatisfied).

**Suggestions for Improvement**

Do you have any suggestions for improving the services offered by First Link?

Are there any resources or supports that you do not currently have access to, but that you think would improve your quality of life and quality of care?

**Additional Comments:** Do you have any additional comments you would like to make about First Link?

## APPENDIX O: Results of the Referral and Service Tracking

### Number of Registered Alzheimer Society Clients

Demonstration Site	Percentage (#)
Ottawa	45.2% (1611)
Kingston	17.8% (634)
Grey Bruce/ Huron/ Perth	16.9% (602)
Sudbury/ Timmins	20.1% (715)
Total	3562

### Date of Referral (N = 3562)

<b>2007</b>	
November	4.3% (153)
December 2007	3.8% (131)
<b>2007 Total</b>	8.0% (284)
<b>2008</b>	
January	6.7% (237)
February	3.6% (129)
March	3.7% (133)
April	6.3% (225)
May	5.0% (177)
June	5.4% (193)
July	5.0% (177)
August	4.4% (156)
September	5.7% (203)
October	5.5% (195)
November	4.4% (155)
December	3.9% (139)
<b>2008 Total</b>	59.5% (2119)
<b>2009</b>	
January	5.7% (204)
February	4.6% (165)
March	5.5% (197)
April	5.0% (179)
May	5.2% (185)
June	4.6% (165)
2009 total	30.7% (1095)
Total	3498

Note: Percentages do not sum to 100% due to missing values.

## Number of Registered Clients Per Alzheimer Society Chapter

Demonstration Site/ Chapter	Percentage (#)
<b><i>Ottawa (N = 1611)</i></b>	
Ottawa	91.2% (1470)
Renfrew County	8.8% (141)
<b><i>Kingston (N = 634)</i></b>	
Kingston	51.3% (325)
Belleville	33.9% (215)
Leeds-Grenville	14.8% (94)
<b><i>Grey Bruce/ Huron/ Perth (N = 602)</i></b>	
Grey Bruce	57.1% (344)
Huron	16.6% (100)
Perth	26.2% (158)
<b><i>Sudbury/ Timmins (N = 715)</i></b>	
Sudbury	90.2% (645)
Timmins	9.8% (70)

## Client Gender

	<b>Ottawa (N = 1611)</b>	<b>Kingston (N = 634)</b>	<b>Grey Bruce/ Huron/ Perth (N = 602)</b>	<b>Sudbury/ Timmins (N = 715)</b>	<b>Total Across Sites (N = 3562)</b>
Female	68.4% (1102)	70.7% (448)	70.6% (425)	65.5% (468)	68.6% (2443)
Male	26.9% (434)	27.8% (176)	25.4% (153)	20.0% (143)	25.4% (906)

## Client Age

	<b>Ottawa (N = 1611)</b>	<b>Kingston (N = 634)</b>	<b>Grey Bruce/ Huron/ Perth (N = 602)</b>	<b>Sudbury/ Timmins (N = 715)</b>	<b>Total Across Sites (N = 3562)</b>
Mean (SD) years	64.22 (14.3)	66.18 (14.0)	67.20 (13.8)	64.52 (14.0)	65.17 (14.1)
Range	23-96	28-92	36-92	27-94	23-96
Number (available data)	321	372	97	423	1214



### Client Relationship to Person with Dementia

Relationship with Person with Dementia	Percentage within Demonstration Site (#)				Total Across Sites (N = 3562)
	Ottawa (N = 1611)	Kingston (N = 634)	Grey Bruce/ Huron/ Perth (N = 602)	Sudbury/ Timmins (N = 715)	
Self	3.5% (57)	5.0% (32)	5.1% (31)	12.2% (87)	5.8% (207)
Child	52.8% (851)	39.7% (252)	43.4% (261)	36.9% (264)	45.7% (1628)
Friend	3.1% (50)	1.3% (8)	2.5% (15)	2.8% (20)	2.6% (93)
Relative	9.2% (149)	6.5% (41)	4.5% (27)	3.4% (24)	6.8% (241)
Sibling	2.9% (47)	1.6% (10)	2.2% (13)	2.1% (15)	2.4% (85)
Spouse	25.1% (404)	44.3% (281)	36.4% (219)	28.0% (200)	31.0% (1104)

### First Language of the Client

Language	Percentage within Demonstration Site (#)				Total Across Sites (N = 3562)
	Ottawa (N = 1611)	Kingston (N = 634)	Grey Bruce/ Huron/ Perth (N = 602)	Sudbury/ Timmins (N = 715)	
French	6.3% (102)	.6% (4)	.2% (1)	10.2% (73)	5.1% (180)

### First Language of the Person with Dementia

Language	Percentage within Demonstration Site (#)				Total Across Sites (N = 3562)
	Ottawa (N = 1611)	Kingston (N = 634)	Grey Bruce/ Huron/ Perth (N = 602)	Sudbury/ Timmins (N = 715)	
Cantonese	.1% (2)	.2% (1)	0	0	.1% (3)
Chinese	.1% (1)	.2% (1)	0	0	.1% (2)
Croatian	.1% (1)	.2% (1)	0	0	.1% (2)
Dutch	.1% (1)	1.4% (9)	1.0% (6)	0	.4% (16)
French	8.8% (142)	1.6% (10)	.3% (2)	9.1% (65)	6.1% (219)
German	.1% (1)	.5% (3)	1.2% (7)	.1% (1)	.3% (12)

Language	Percentage within Demonstration Site (#)				Total Across Sites (N = 3562)
	Ottawa (N = 1611)	Kingston (N = 634)	Grey Bruce/ Huron/ Perth (N = 602)	Sudbury/ Timmins (N = 715)	
Greek	.1% (1)	0	0	0	.0% (1)
Italian	.4% (7)	.5% (3)	.2% (1)	.7% (5)	.4% (16)
Polish	.2% (4)	.6% (4)	0	0	.2% (8)
Slovakian	.1% (1)	0	0	0	.0% (1)
Spanish	.2% (4)	0	0	0	.1% (4)
Ukrainian	.1% (1)	.5% (3)	0	0	.1% (4)
Vietnamese	.1% (2)	0	0	0	.1% (2)
<b>First Language Not English</b>	10.4% (168)	5.5% (35)	2.7% (16)	10.1% (972)	291 (8.2%)

### Gender of the Person with Dementia

	Ottawa (N = 1611)	Kingston (N = 634)	Grey Bruce/ Huron/ Perth (N = 602)	Sudbury/ Timmins (N = 715)	Total Across Sites (N = 3562)
Female	54.1% (872)	54.9% (348)	47.2% (284)	50.5% (361)	52.4% (1866)
Male	34.8% (560)	39.0% (247)	36.9% (222)	35.1% (251)	35.9% (1280)

Note: Percentages do not sum to 100% due to missing values.

### Age of the Person with Dementia

	Ottawa (N = 1611)	Kingston (N = 634)	Grey Bruce/ Huron/ Perth (N = 602)	Sudbury/ Timmins (N = 715)	Total Across Sites (N = 3562)
Mean (SD)	80.66 (8.2)	80.33 (7.8)	80.67 (7.9)	80.34 (8.4)	80.54 (8.1)
Range	45-101	54-100	48-97	46-96	45-101
Number (available data)	782	341	289	344	1759

### Diagnosis

Diagnosis	Percentage within Demonstration Site (#)				Total Across Sites (N = 3562)
	Ottawa (N = 1611)	Kingston (N = 634)	Grey Bruce/ Huron/ Perth (N = 602)	Sudbury/ Timmins (N = 715)	
AD	46.4% (748)	39.7% (252)	40.2% (242)	21.0% (150)	39.1% (1392)
Dementia	23.5% (379)	22.2% (141)	9.1% (55)	13.8% (99)	18.9% (674)
Mixed Dementia*	10.4% (168)	8.8% (56)	6.0% (36)	.7% (5)	7.4% (265)
FTD	.8% (13)	.8% (5)	1.2% (7)	.8% (6)	.9% (31)
Lewy Body	.7% (12)	2.1% (13)	.8% (5)	.8% (6)	1.0% (36)
MCI	.9% (15)	.2% (1)	.7% (4)	.1% (1)	.6% (21)

Diagnosis	Percentage within Demonstration Site (#)				Total Across Sites (N = 3562)
	Ottawa (N = 1611)	Kingston (N = 634)	Grey Bruce/ Huron/ Perth (N = 602)	Sudbury/ Timmins (N = 715)	
Parkinsons	.2% (4)	.5% (3)	.3% (2)	0	.3% (9)
Picks	.3% (5)	0	.3% (2)	.1% (1)	.2% (8)
Vascular	3.3% (53)	7.4% (47)	2.5% (15)	2.4% (17)	3.7% (132)
Under Investigation	1.7% (28)	6.9% (44)	8.3% (50)	.8% (6)	3.6% (128)
Without diagnosis	4.8% (77)	6.6% (42)	9.5% (57)	46.3% (331)	14.2% (507)

\* Mixed Dementia: More than one type of dementia noted in the diagnosis

### Other Diagnoses: Across All Sites

	Percentage (#)
Total number of individuals with a diagnosis (other than ADRD)	6.8% (245)
Number of diagnoses per person: Mean (SD)	1.4 (.85)
<b>Other Diagnoses (N = 3562)</b>	
Blood/ endocrine issues (anemia, high cholesterol, low potassium)	.3% (10)
Bone and joint conditions (arthritis, osteoarthritis, osteoporosis, replacements, fractures)	.8% (29)
Cancer	.5% (18)
Cardiovascular disease (heart attack, angina)	1.1% (39)
Cerebrovascular disease (hypertension, stroke)	2.0% (73)
Diabetes	1.0% (36)
Mental illness (depression, anxiety, personality disorders)	1.3% (46)
Substance abuse (drug, alcohol)	.3% (11)
Visual conditions (blindness, cataracts, glaucoma, macular degeneration)	.5% (18)
<b>Other</b>	
Communication impairments (aphasia)	.2% (6)
Delirium	.1% (4)
Genetic disorders (Downs Syndrome, Fragile X)	.2% (7)
Hearing disorders/ impairments	.2% (6)
Parkinson's disease	.1% (4)
Renal conditions (kidney failure, kidney stones)	.2% (6)
Respiratory disease (COPD, emphysema, asthma)	.3% (9)
Thyroid conditions	.2% (6)

	Percentage (#)
Miscellaneous* (prostrate, urinary tract infection, pain syndrome, amnesia, head injury, shingles, Multiple sclerosis, Korsakoff's syndrome, sleep disorders, multi-system atrophy)	.5% (18)

\*diagnoses identified for 3 or fewer individuals

### Person with Dementia Living Arrangement

Living Arrangement	Percentage within Demonstration Site (#)				Total Across Sites (N = 3562)
	Ottawa (N = 1611)	Kingston (N = 634)	Grey Bruce/ Huron/ Perth (N = 602)	Sudbury/ Timmins (N = 715)	
Alone	8.8% (141)	16.1% (102)	7.8% (47)	12.6% (90)	10.7% (380)
Institution	0	.6% (4)	0	.1% (1)	.1% (5)
With Care partner	.2% (3)	.2% (1)	.8% (5)	.4% (3)	.3% (12)

### PWD Has a Family Physician

Family Physician?	Percentage within Demonstration Site (#)				Total Across Sites (N = 3562)
	Ottawa (N = 1611)	Kingston (N = 634)	Grey Bruce/ Huron/ Perth (N = 602)	Sudbury/ Timmins (N = 715)	
Yes	40.8% (657)	78.7% (499)	46.2% (282)	73.4% (525)	55.1% (1963)

### Clients Registered with a Second Person with Dementia

	Percentage within Demonstration Site (#)				Total Across Sites (N = 3562)
	Ottawa (N = 1611)	Kingston (N = 634)	Grey Bruce/ Huron/ Perth (N = 602)	Sudbury/ Timmins (N = 715)	
Second Person with Dementia	1.4% (22)	.8% (5)	1.3% (8)	1.0% (7)	1.2% (42)

### Existing Community Services

Service	Percentage within Demonstration Site (#)				Total Across Sites (N = 3562)
	Ottawa (N = 1611)	Kingston (N = 634)	Grey Bruce/ Huron/ Perth (N = 602)	Sudbury/ Timmins (N = 715)	
CCAC	2.4% (38)	22.6% (143)	18.4% (111)	22.4% (160)	12.7% (452)
Community Home Support	.2% (3)	2.4% (15)	5.5% (33)	3.5% (25)	2.1% (76)
Community Services	.6% (9)	5.5% (35)	6.1% (37)	2.8% (20)	2.8% (101)

Service	Percentage within Demonstration Site (#)				Total Across Sites (N = 3562)
	Ottawa (N = 1611)	Kingston (N = 634)	Grey Bruce/ Huron/ Perth (N = 602)	Sudbury/ Timmins (N = 715)	
Day Away Program	.2% (4)	4.1% (26)	2.8% (17)	1.0% (7)	1.5% (54)
VAP	.2% (4)	1.6% (10)	.8% (5)	1.4% (10)	.8% (29)

### Average Number of Existing Services

	Percentage within Demonstration Site (#)				Total Across Sites (N = 3562)
	Ottawa (N = 44)	Kingston (N = 181)	Grey Bruce/ Huron/ Perth (N = 154)	Sudbury/ Timmins (N = 182)	
Mean (SD)	1.32 (.67)	1.27 (.53)	1.32 (.52)	1.22 (.62)	1.27 (.57)
Range	1 - 5	1 - 4	1 - 3	1 - 3	1 - 5

### Person with Dementia: Death or Placement During Demonstration Phase

	Percentage within Demonstration Site (#)				Total Across Sites (N = 3562)
	Ottawa (N = 1611)	Kingston (N = 634)	Grey Bruce/ Huron/ Perth (N = 602)	Sudbury/ Timmins (N = 715)	
Death	3.4% (53)	4.4% (28)	2.5% (15)	1.1% (8)	2.9% (104)
Placement (Long-term care, nursing home)	5.0% (80)	10.4% (66)	5.6% (34)	0	5.1% (180)

### Time from Diagnosis to Referral

Time to Referral	Ottawa (N = 1000)	Kingston (N = 237)	Grey Bruce/ Huron/ Perth (N=211)	Sudbury/ Timmins (N = 519)	Total Across Sites (N = 1967)
More than 13 months before diagnosis	.2% (2)	.4% (1)	.5% (1)	0	.2% (4)
9-12 months before diagnosis	.8% (8)	0	.9% (2)	.4% (2)	.6% (12)
5-8 months before diagnosis	1.2% (12)	.8% (2)	1.4% (3)	.6% (3)	1.0% (20)
2 -4 months before	1.5% (15)	.8% (2)	.9% (2)	1.0% (5)	1.2% (24)

<b>Time to Referral</b>	<b>Ottawa (N = 1000)</b>	<b>Kingston (N = 237)</b>	<b>Grey Bruce/ Huron/ Perth (N=211)</b>	<b>Sudbury/ Timmins (N = 519)</b>	<b>Total Across Sites (N = 1967)</b>
diagnosis					
Within 1 month before diagnosis	1.3% (13)	1.7% (4)	.9% (2)	1.0% (5)	1.2% (24)
Same month as diagnosis	41.8% (418)	55.3% (131)	10.9% (23)	72.6% (377)	48.2% (949)
Within 1 month of diagnosis	9.0% (90)	7.2% (17)	4.7% (10)	.6% (3)	6.1% (120)
2 -4 months after diagnosis	11.2% (112)	8.0% (19)	12.8% (27)	1.3% (7)	8.4% (165)
5-8 months after	5.8% (58)	5.5% (13)	4.3% (9)	2.7% (14)	4.8% (94)
9 -12 months after	5.5% (55)	5.1% (12)	8.5% (18)	3.3% (17)	5.2% (102)
13 -18 months after	4.4% (44)	4.6% (11)	9.5% (20)	2.3% (12)	4.4% (87)
19-24 months after	4.6% (46)	3.0% (7)	4.7% (10)	3.1% (16)	4.0% (79)
25-36 months (3 yrs)	4.2% (42)	3.4% (8)	10.4% (22)	3.1% (16)	4.5% (88)
37-48 months (4 yrs)	2.8% (28)	2.1% (5)	10.4% (22)	2.9% (15)	3.6% (70)
49-60 months (5 yrs)	1.9% (19)	1.3% (3)	3.8% (8)	1.7% (9)	2.0% (39)
61-72 months (6 yrs) after	1.4% (14)	.4% (1)	3.8% (8)	1.0% (5)	1.4% (28)
73-84 months (7 yrs)	1.0% (10)	0	4.3% (9)	.8% (4)	1.2% (23)
85-96 months (8 yrs)	.4% (4)	.4% (1)	1.4% (3)	.6% (3)	.6% (11)
97-10 months (9 yrs)	.5% (5)	0	1.4% (3)	.4% (2)	.5% (10)
109-120 months (10 yrs)	.1% (1)	0	0	.4% (2)	.2% (3)
greater than 120 months (11 yrs)	.4% (4)	0	4.3% (9)	.4% (2)	.8% (15)

#### **Time from Diagnosis to Referral (Collapsed)**

<b>Time to Referral</b>	<b>Ottawa (N = 1000)</b>	<b>Kingston (N = 237)</b>	<b>Grey Bruce/ Huron/ Perth (N=211)</b>	<b>Sudbury/ Timmins (N = 519)</b>	<b>Total Across Sites (N = 1967)</b>
Before diagnosis	5.0% 50	3.8% (9)	4.7% (10)	2.9% (15)	4.3% (84)
Same month	47.8% (418)	55.3% (131)	10.9% (23)	72.6% (377)	48.2% (949)
Within 1 year	31.5% (315)	25.7% (61)	30.3% (64)	7.9% (41)	24.5% (481)
13-36 months (2-3 yrs)	13.2% (132)	11.0% (26)	24.6% (52)	8.5% (44)	12.9% (254)
More than 4 years after diagnosis	13.2% (85)	4.2% (10)	29.4% (62)	8.1% (42)	10.1% (199)

### Average Time from Diagnosis to Referral (Month)

	<b>Ottawa (N = 1000)</b>	<b>Kingston (N = 237)</b>	<b>Grey Bruce/ Huron/ Perth (N = 211)</b>	<b>Sudbury/ Timmins (N = 519)</b>	<b>Total Across Sites (N = 1967)</b>
Mean (SD)	9.63 (19.92)	5.7 (12.95)	27.6 (33.66)	7.85 (20.21)	10.61 (22.06)
Range*	-14 - 146	-14 - 94	-14.00 - 148	-10 - 146	-14 - 148

Negative values refer to referral prior to diagnosis.

**Differences between sites:** ANOVA:  $F(3,1963) = 52.9$ ,  $p = .000$  (Grey Bruce/Huron/Perth has a significantly higher average time from diagnosis to referral than the other sites).

### Learning Series Attendance

	<b>Ottawa (N = 1611)</b>	<b>Kingston (N = 634)</b>	<b>Grey Bruce/ Huron/ Perth (N = 602)</b>	<b>Sudbury/ Timmins (N = 715)</b>	<b>Total Across Sites (N = 3562)</b>
Attended Learning Series (% of total attendance)	14.0% (226)	21.9% (139)	16.3% (98)	15.7% (112)	16.1% (575)
% Within each site	6.3% (226)	3.9% (139)	2.8% (98)	3.1% (112)	

	<b>Ottawa (N = 1611)</b>	<b>Kingston (N = 634)</b>	<b>Grey Bruce/ Huron/ Perth (N = 602)</b>	<b>Sudbury/ Timmins (N = 715)</b>	<b>Total Across Sites (N = 3562)</b>
Alzheimer Society Education Programs	6.8% (110)	6.6% (42)	12.8% (77)	1.4% (10)	6.7% (239)
Advanced Care Planning	.1% (2)	.9% (6)	3.0% (18)	.4% (3)	.8% (29)
Alzheimer Society Resources	6.1% (98)	3.5% (22)	11.8% (71)	.3% (2)	5.4% (193)
Individual Support	5.8% (93)	3.2% (20)	29.9% (180)	10.4% (75)	10.3% (368)
Safely Home	3.2% (51)	13.7% (50)	8.1% (49)	37.9% (271)	11.8% (421)

Support Groups for Caregivers	5.2% (84)	11.0% (70)	31.6% (190)	18.6% (133)	13.4% (477)
Support Groups for Persons with Dementia	.7% (11)	4.9% (31)	3.5% (21)	34.5% (247)	8.7% (310)
Respite	4.8% (56)	9% (57)	5.1% (31)	27.4% (196)	9.5% (340)
CCAC	5.3% (86)	6.9% (44)	10.1% (36)	1.5% (11)	5.7% (202)
Day Away	3.7% (59)	6.0% (38)	6.0% (36)	37.9% (271)	11.3% (404)
Placement	.7% (11)	1.6% (10)	.7% (4)	0	7.0% (25)
Community Agencies Programs	3.3% (53)	6.3% (40)	4.0% (24)	.9% (6)	3.5% (123)

## REFERRAL STATUS: Self-referred vs. Referred via First Link

### Self-referrals

	Ottawa (N = 1611)	Kingston (N = 634)	Grey Bruce/ Huron/ Perth (N = 602)	Sudbury/ Timmins (N = 715)	Total Across Sites (N = 3562)
Self-referred	26.0% (419)	34.4% (218)	74.6% (449)	24.5% (175)	35.4% (1261)
Referred via First Link	74.0% (1192)	65.6% (416)	25.4% (153)	75.5% (540)	64.6% (2301)

**Differences between sites:**  $\chi^2(3) = 503.9$ ,  $p = .000$  (greater percentage of clients from Grey Bruce/Huron/Perth were self-referred than the other sites)

**Differences between referral status:**  $\chi^2(1) = 303.7$ ,  $p = .000$  (greater percentage of first link clients were Referred via First Link).

### Self-referrals: Source of information about First Link

	Percentage calculated within Source of Information				Total Across All Self- referrals (N = 1261)	$\chi^2(3)$
	Ottawa (N = 419)	Kingston (N = 218)	Grey Bruce/ Huron/ Perth (N = 449)	Sudbury/ Timmins (N = 175)		
Alzheimer Society	11.0% (49)	20.0% (98)	59.9% (267)	7.2% (32)	35.4% (446)	736.4*
Friends/	41.1% (81)	8.6% (19)	26.4% (52)	22.8% (45)	15.6% (197)	20.5*



	Percentage calculated within Source of Information				Total Across All Self-referrals (N = 1261)	$\chi^2$ (3)
	Ottawa (N = 419)	Kingston (N = 218)	Grey Bruce/Huron/Perth (N = 449)	Sudbury/Timmins (N = 175)		
Family						
Education Session	11.3% (7)	40.3% (25)	22.6% (14)	25.8% (16)	4.9% (62)	36.3*
Family Physician	39.8% (39)	19.4% (19)	21.4% (21)	19.4% (19)	7.8% (98)	n.s
Public Awareness/Com. Groups	52.9% (139)	11.2% (29)	22.5% (58)	12.4% (32)	20.5% (258)	24.6*
Media	42.5% (77)	9.9% (18)	26.5% (48)	20.0% (38)	14.4% (181)	17.4*
Specialist	61.2% (41)	20.8% (14)	13.4% (9)	4.5% (3)	5.3% (67)	13.0*

Note: Percentage within sites exceeds 100% because some individuals identified more than one source of information about First Link

**Differences between sites in sources of information:**

*Alzheimer Society:*  $\chi^2$  (3) = 736.4, p = .000 (higher percentage of those who heard about First Link from the Alzheimer Society were from Grey Bruce/Huron/Perth site than the other sites).

*Friends/Family* =  $\chi^2$  (3) = 20.5, p = .000 (higher percentage of those who heard about First Link from the Friends/Family were from the Ottawa site than the other sites).

*Education Session:*  $\chi^2$  (3) = 36.3, p = .000 (higher percentage of those who heard about First Link from an education session were from the Kingston site than the other sites).

*Family Physicians:*  $\chi^2$  (3) = n.s. (no differences between sites in the percentage of self-referrals that heard about First Link from family physicians).

*Public Awareness/Community Groups:*  $\chi^2$  (3) = 24.6, p = .000 (higher percentage of those who heard about First Link through Public awareness/community groups were from Ottawa site than the other sites).

*Media:*  $\chi^2$  (3) = 17.4, p = .005 (higher percentage of those who heard about First Link from a Specialist were from Ottawa site than other sites).

*Specialist:*  $\chi^2$  (3) = 13.0, p = .005 (higher percentage of those who heard about First Link from a Specialist were from Ottawa site than other sites).

**Non-Self-referrals: Referral Source**

	Percentage calculated within Referral Source				Total Across All Referrals (N = 2301)	$\chi^2$ (3)
	Ottawa (N = 1192)	Kingston (N = 416)	Grey Bruce/Huron/Perth (N = 153)	Sudbury/Timmins (N = 546)		
CCAC	22.1% (66)	9.7% (29)	28.8% (86)	39.5% (118)	13.0% (299)	139.0*

	Percentage calculated within Referral Source				Total Across All Referrals (N = 2301)	$\chi^2$ (3)
	Ottawa (N = 1192)	Kingston (N = 416)	Grey Bruce/Huron/Perth (N = 153)	Sudbury/Timmins (N = 546)		
Community Services	21.9% (23)	37.1% (39)	10.5% (11)	30.5% (32)	4.6% (105)	44.2*
Senior Centres	0	0	20.0% (2)	80.0% (8)	.4% (10)	n.a
Day Away Programs	66.7% (8)	16.7% (2)	8.3% (1)	8.3% (1)	.5% (12)	n.s.
Family Physicians	12.6% (47)	28.2% (105)	12.6% (47)	46.6% (174)	16.2% (373)	274.3*
Specialist	75.6% (592)	22.0% (172)	.8% (6)	1.7% (702)	34.0% (783)	538.7*
Nurse Practitioner	0	0	100% (2)	0	.09% (2)	n.a

Note: In some cases more than one referral source was identified, in other cases the referral sources was not specified.

\*p<.001; n.s = not significant; n.a. = not applicable as unable to calculate.

#### ***Differences between sites:***

*CCAC:*  $\chi^2$  (3) = 139.0, p = .000 (higher percentage of those referred by CCAC were from Grey Bruce/Huron/Perth and Sudbury/Timmins sites than the other sites).

*Community Service:*  $\chi^2$  (3) = 44.2, p = .000 (higher percentage of those who were referred by community services were from the Kingston site than the other sites).

*DAP:*  $\chi^2$  (3) = n.s. (no differences between sites in the percentage of referrals from DAP)

*Family Physicians:*  $\chi^2$  (3) = 274.3, p = .000 (higher percentage of those referred by family physicians were from the Kingston and Sudbury/Timmins sites).

*Specialist:*  $\chi^2$  (3) = 538.7, p = .000 (higher percentage of those who were referred by specialists were from the Ottawa and Kingston sites).

#### **REFERRAL SOURCE BY SITE: Community Health Centre/ Family Health Team**

	Ottawa (N = 1611)	Kingston (N = 634)	Grey Bruce/Huron/Perth (N = 602)	Sudbury/Timmins (N = 715)	Total Across Sites (N = 3562)
Community Health Centre	.3% (5)	1.4% (9)	.3% (2)	1.3% (9)	.7% (25)
Family Health Teams	.6% (10)	14.7% (93)	4.5% (27)	5.5% (39)	4.7% (169)

**REFERRAL SOURCE BY REFERRAL STATUS:  
Community Health Centre/ Family Health Team**

	<b>Self-referred (N = 1261)</b>	<b>Referred via First Link (N = 2301)</b>	<b>Total (N = 3562)</b>
Community Health Centre	.23% (3)	1.0% (22)	.7% (25)
Family Health Teams	1.1% (14)	6.7% (155)	4.7% (169)

**Relationship to Person with Dementia**

	<b>Self-referred (N = 1261)</b>	<b>Referred via First Link (N = 2301)</b>	<b>Total (N = 3562)</b>
Child	46.9% (592)	45.0% (1036)	45.7% (1628)
Friend	2.5% (32)	2.7% (61)	2.6% (93)
Relative	5.9% (74)	7.3% (167)	6.8% (241)
Self	5.9% (75)	5.7% (132)	5.8% (207)
Sibling	2.9% (37)	2.1% (48)	2.4% (85)
Spouse	32.0% (404)	30.4% (700)	31.0% (1104)

**Client Gender**

	<b>Self-referred (N = 1261)</b>	<b>Referred via First Link (N = 2301)</b>	<b>Total (N = 3562)</b>
Female	73.2% (923)	66.1% (1520)	68.6% (2443)
Male	23.7% (299)	26.4% (607)	25.4% (906)

**Client Age**

	<b>Self-referred (N = 1261)</b>	<b>Referred via First Link (N = 2301)</b>	<b>Total (N = 3562)</b>
Mean (SD) years	63.9 (14.2)	65.8 (14.0)	65.2 (14.1)
Range	27-96	23-92	23-96
Number (available data)	384	830	1214

### First Language of Client

	Self-referred (N = 1261)	Referred via First Link (N = 2301)	Total (N = 3562)
French	4.3% (54)	5.5% (126)	5.1% (180)

### Person with Dementia: English as a Second Language

	Self-referred (N = 1261)	Referred via First Link (N = 2301)	Total (N = 3562)
English as second language	7.5% (95)	8.5% (196)	8.2% (291)

### Gender of the Person with Dementia

	Self-referred (N = 1261)	Referred via First Link (N = 2301)	Total (N = 3562)
Female	52.1% (657)	52.5% (1209)	52.4% (1866)
Male	36.3% (458)	35.7% (822)	35.9% (1280)

Note: Percentages do not sum to 100% due to missing values.

### Age of the Person with Dementia

	Self-referred (N = 1261)	Referred via First Link (N = 2301)	Total (N = 3562)
Mean (SD) years	80.4 (7.8)	80.6 (8.2)	80.5 (8.1)
Range	49-100	45-101	45-101
Number (available data)	625	1134	1759

### Diagnosis

Diagnosis	Self-referred (N = 1261)	Referred via First Link (N = 2301)	Total (N = 3562)
AD	45.2% (570)	35.7% (822)	39.1% (1392)
Dementia	15.8% (199)	20.6% (475)	18.9% (674)
FTD	1.0% (13)	.8% (18)	.9% (31)
Lewy Body	1.2% (15)	.9% (21)	1.0% (36)

MCI	.3% (4)	.7% (17)	.6% (21)
Mixed	4.9% (62)	8.8% (203)	7.4% (265)
Parkinsons	.3% (4)	.2% (5)	.3% (9)
Picks	.2% (3)	.2% (5)	.2 (8)
Under Investigation	4.8% (60)	3.0% (68)	3.6% (128)
Vascular	3.5% (44)	3.8% (88)	3.7% (132)
Without diagnosis	13.8% (174)	14.5% (333)	14.2% (507)

### Person with Dementia Living Arrangements

	Self-referred (N = 1261)	Referred via First Link (N = 2301)	Total (N = 3562)
Alone	9.8% (124)	11.1% (256)	10.7% (380)
Institution	.2% (3)	.1% (20)	.1% (5)
With Care partner	.6% (7)	.2% (5)	.3% (12)

### Person with Dementia Has Family Physician

	Self-referred (N = 1261)	Referred via First Link (N = 2301)	Total (N = 3562)
Yes	46.9% (591)	59.6% (1372)	55.1% (1963)

*Differences between referral status:*  $\chi^2(1) = 53.6$ ,  $p = .000$  (greater percentage of those who were referred via First Link have a family physician)

### Clients Registered with a Second Person with Dementia

	Self-referred (N = 1261)	Referred via First Link (N = 2301)	Total (N = 3562)
Second person with dementia	1.2% (15)	1.2% (27)	1.2% (42)

### Existing Community Services

	Self-referred (N = 1261)	Referred via First Link (N = 2301)	Total (N = 3562)
CCAC	9.8% (124)	14.3% (328)	12.7% (452)
Community Home Support	3.0% (38)	1.7% (38)	2.1% (76)
Community Services	3.3% (42)	2.6% (59)	2.8% (101)

Day Away Program	1.1% (14)	1.7% (40)	1.5% (54)
VAC	.7% (9)	.9% (20)	.8% (29)

### Average Number of Existing Services

	Self-referred (N = 1261)	Referred via First Link (N = 2301)	Total (N = 3562)
Mean (SD)	1.25 (.45)	1.28 (.57)	1.27 (.57)
Range	1 - 3	1 - 5	1 - 5

Differences between referral status: ANOVA = n.s.

### Death or Placement during Demonstration Phase

	Self-referred (N = 1261)	Referred via First Link (N = 2301)	Total (N = 3562)
Death	2.9% (37)	3.1% (71)	3.0% (108%)
Placement (long-term care/ nursing home)	5.5% (69)	4.8% (111)	5.1% (180)

### Time from Diagnosis to Referral

Time from diagnosis to referral	Self-referred (N = 627)	Referred via First Link (N = 1340)	Total (N = 1967)
More than 13 months before diagnosis	.3% (2)	.1% (2)	.2% (4)
9-12 months before diagnosis	.3% (2)	.7% (10)	.6% (12)
5-8 months before diagnosis	1.0% (6)	1.0% (14)	1.0% (20)
2 -4 months before diagnosis	1.4% (9)	1.1% (15)	1.2% (24)
Within 1 month before diagnosis	1.6% (10)	1.0% (14)	1.2% (24)
Same month as diagnosis	27.4% (172)	58.0% (777)	48.2% (949)
Within 1 month of diagnosis	5.7% (36)	6.3% (84)	6.1% (120)
2 -4 months after diagnosis	10.2% (64)	7.5% (101)	8.4% (165)
5-8 months after	5.1% (32)	4.6% (62)	4.8% (94)
9 -12 months after	7.2% (45)	4.3% (57)	5.2% (102)
13 -18 months after	6.7% (42)	3.4% (45)	4.4% (87)
19-24 months after	7.8% (49)	2.2% (30)	4.0% (79)
25-36 months (3 yrs)	8.8% (55)	2.5% (33)	4.5% (88)
37-48 months (4 yrs)	6.1% (38)	2.4% (32)	3.6% (70)
49-60 months (5 yrs)	3.2% (20)	1.4% (19)	2.0% (39)

<b>Time from diagnosis to referral</b>	<b>Self-referred (N = 627)</b>	<b>Referred via First Link (N = 1340)</b>	<b>Total (N = 1967)</b>
61-72 months (6 yrs) after	1.9% (12)	1.2% (16)	1.4% (28)
73-84 months (7 yrs)	2.1% (13)	.7% (10)	1.2% (23)
85-96 months (8 yrs)	.8% (5)	.4% (6)	.6% (11)
97-10 months (9 yrs)	.6% (4)	.4% (6)	.5% (10)
109-120 months (10 yrs)	.2% (1)	.1% (2)	.2% (3)
greater than 120 months (11 yrs)	1.6% (10)	.4% (5)	.8% (15)

### **Time from Diagnosis to Referral (Collapsed)**

<b>Time from diagnosis to referral</b>	<b>Self-referred (N = 627)</b>	<b>Referred via First Link (N = 1340)</b>	<b>Total (N = 1967)</b>
Before diagnosis	4.6% (29)	4.1% (55)	4.3% (84)
Same month	27.4% (172)	58.0% (777)	48.2% (949)
Within 1 year	28.2% (177)	22.7% (304)	24.5% (481)
13-36 months (2-3 yrs)	23.3% (146)	8.1% (108)	12.9% (254)
More than 4 years after diagnosis	16.4% (103)	7.2% (96)	10.1% (199)

*Differences between referral status:*  $\chi^2(4) = 201.2$ ,  $p = .000$  (greater percentage of those who were referred via First Link were connected to First Link in the same month as the diagnosis than those self-referred)

### **Average Time from Diagnosis to Referral (Months)**

<b>Time from diagnosis to referral</b>	<b>Self-referred (N = 627)</b>	<b>Referred via First Link (N = 1340)</b>	<b>Total (N = 1967)</b>
Mean (SD)	17.76 (26.50)	7.27 (18.74)	10.6 (22.06)
Range	-14 - 148	-14 - 146	-14 - 148

*Differences between referral status:* ANOVA =  $f(1, 1965) = 101.5$ ,  $p = .000$

### **Attended Learning Series**

	<b>Referral Status</b>	
	<b>Self-referred</b>	<b>Referred via First Link</b>
N = 575		
Attended Learning Series	40.5% (233)	59.5 (342)

*Differences between referral status:*  $\chi^2(1) = 7.8$ ,  $p = .005$  (greater percentage of those who attended the learning series were referred via First Link than self-referred)

## APPENDIX P: Results of the Information and Public Awareness Activities Tracking

Activities	Ottawa	Kingston/ Belleville/ Prince Edward County	Leeds- Grenville	Grey Bruce/ Huron/ Perth	Sudbury/ Timmins	TOTAL
<b>Awareness Raising</b>						
Awareness raising activities {# direct hours}	268	737	369	173	341	1,887
Awareness raising activities (# served)	1,847	785	782	1,813	3,126	8,353
<b>Education</b>						
Number of Information packages mailed out	1,812	517	87	469	654	3,539
Number of Information packages mailed without contact	76	78	1	5	3	163
Learning Series Attendance	880	545	313	181	714	2,633
Education {direct hours}	625	734	176	806	390	2,730
Education {number served}	2,820	975	764	432	1,010	6,001
<b>Community Consultation</b>						
Community Consultation (# direct hours}	642	103	231	120	224	1,320
Community Consultation (# served}	2,552	33	74	325	697	3,681
<b>Volunteer Services</b>						
Volunteers {# direct hours}	359	45	245	68	70	786
Volunteers {# served}	84	288	381	6	66	825
<b>Client Contacts</b>						
Number of client contacts	7,337	1,068	491	1,396	1,232	11,524
Client/ Caregiver Support {# direct hours}	598	606	126	28	605	1,962
Client/Caregiver Support {# served}	3,900	445	423	70	961	5,799



## APPENDIX Q: Results of the Caregiver Survey

### Response Rate

Site		First Survey (Baseline)	Second Survey (Follow-up #1)	Third Survey (Follow-up #2)	Fourth Survey (Follow-up #3)	Fifth Survey (Follow-up #4)
Ottawa	# Distributed	170	24	17	8	n/a
	# Completed	24	17	8	3	--
	Response Rate	14.1%	70.8%	47.1%	37.5%	--
Grey Bruce/ Huron/ Perth	# Distributed	241	25	20	16	n/a
	# Completed	25	20	17	6	--
	Response Rate	10.4	80.0%	85.0%	37.5%	--
Kingston	# Distributed	162	24	20	14	2
	# Completed	24	20	14	8	2
	Response Rate	14.8%	83.3%	70.0%	57.1%	100%
Sudbury/ Timmins	# Distributed	263	19	10	3	n/a
	# Completed	19	10	3	2	--
	Response Rate	7.2%	52.6%	30.0%	66.7%	--
<b>TOTAL</b>	# Distributed	836	92	67	41	2
	# Completed	92	67	42	19	2
	Response Rate	11.0%	72.8%	62.7%	46.3%	100%

**Note:** For the results of the caregiver surveys presented here percentages for the first survey are based on N = 92, for the remaining surveys percentages are calculated based on the number of surveys that were distributed for that particular survey (i.e., N = 92 for survey #2, N = 67 for survey #3, N = 41 for survey #4 and N = 2 for survey #5. Significant differences in survey responses between demonstration sites and survey times are identified where relevant.

### HEALTH INFORMATION

**Please select the one statement that best describes the person you are caring for:**

This person has been formally diagnosed with Alzheimer Disease or a related dementia

This person has not been diagnosed with Alzheimer Disease or a related dementia, but has experienced memory loss or other similar symptoms.

Site	Formal Diagnosis of ADRD	Memory loss or similar symptoms
<b>First Survey Only</b>		
Sudbury/ Timmins (N = 19)	31.6% (6)	21.1% (4)
Kingston (N = 25)	20.0% (5)	0
Ottawa (N = 24)	58.3% (14)	0
Grey Bruce/ Huron/ Perth (N = 24)	54.2% (13)	12.5% (3)
<b>Across all sites (N = 92)</b>	<b>41.3% (38)</b>	<b>7.6% (7)</b>

Note: Percentages do not sum to 100% due to missing values. This question was asked only in the first survey and was added to the survey at a later date (October 2008).

**Differences in diagnosis status:** More persons with dementia have a formal diagnosis of ADRD (41%) than those who have not been diagnosed with ADRD, but have experienced memory loss or other similar symptoms (7%),  $\chi^2(1) = 21.4$ ,  $p < .001$ .

**Does the person you are caring for who has recently been diagnosed with Alzheimer disease or a related dementia<sup>15</sup> have any of the following conditions? Please check all that apply.**

Condition	First Survey (N = 92) Baseline	Survey #2 (N = 92) FUp #1	Survey #3 (N = 67) FUp #2	Survey #4 (N = 41) FUp #3	Survey #5 (N = 2) FUp #4
Arthritis/osteoarthritis	42.4% (39)	12.0% (10)	1.5% (1)	4.9% (2)	0
Osteoporosis	25.0% (23)	3.3% (3)	1.5% (1)	4.9% (2)	0
Cancer	8.7% (8)	4.3% (4)	0	2.4% (1)	0
Heart attack, angina (cardiovascular disease)	29.3% (27)	2.2% (2)	4.5% (3)	46.3% (19)	100% (2)
Diabetes	22.8% (21)	3.3% (3)	3.0% (2)	46.3% (19)	0
High blood pressure, stroke (cerebrovascular disease)	50.0% (46)	8.7% (8)	3.0% (2)	2.4% (1)	0
Depression	31.5% (29)	4.3% (4)	7.5% (5)	2.4% (1)	0
Psychosis or personality disorder (other psychiatric disorders)	6.5% (6)	2.2% (2)	3.0% (2)	46.3% (19)	0
COPD, emphysema, asthma (respiratory diseases)	9.8% (9)	1.1% (1)	0	2.4% (1)	0

<sup>15</sup> This includes those who have not been diagnosed with Alzheimer Disease or a related dementia, but has experienced memory loss or other similar symptoms.

<b>Condition</b>	<b>First Survey (N = 92) Baseline</b>	<b>Survey #2 (N = 92) FUp #1</b>	<b>Survey #3 (N = 67) FUp #2</b>	<b>Survey #4 (N = 41) FUp #3</b>	<b>Survey # 5 (N = 2) FUp #4</b>
Problems with drugs or alcohol	2.2% (2)	0	0	0	0
Other	22.8% (21)	10.7% (10)	3.0% (2)	0	50.0% (1)
Mean number of conditions per person (SD)	2.6 (1.9)	1.2 (.80)	.45 (.80)	.63 (1.1)	1.0 (.00)
Range	0* - 9	0* - 7	0* - 3	0 - 4	1
N	92	66	42	19	2

Note: Percentages may not sum to 100% due to missing values.

\*Survey #1: 10 individuals (10.9%) identified no health conditions; Survey #2: 36 individuals (39.1%); Survey #3: 30 individuals (44.1%) identified no health conditions; Survey #4: 13 individuals (31.7%) identified no health conditions.

### **Other conditions included:**

#### **As identified in First Survey (one each):**

- *balance problems - unsteady mobility*
- *had shock treatments in the early 1980's*
- *High cholestrol and hypo thyroidism*
- *Hyper parathyroidism, reflux, weak bladder, gas*
- *Liver transplant 2002 - never the same since*
- *low blood pressure*
- *Macular degeneration*
- *Myelodysplasia, Brain tumor (meningioma) - Catscan of Oct 07 shows the tumor has tripled in size in 2 years*
- *obesity*
- *Parkinson's Disease*
- *Parkinson's Disease for 13 years*
- *scratches chin, face, & forehead*
- *sleep apnea*
- *successful kidney transplant in 2002*
- *Thyroid*

#### **As identified in the first follow-up survey:**

- *Alzheimer disease, 2. Generalized weakness,*
- *mylodysplatis*
- *Fast pulse rate*
- *Does seem depressed at times and frustrated with disease process.*
- *lewy body dementia*

- *Lewy body disease*
- *Lost her ability to walk*
- *Parkinson's disease*
- *waiting for a knee replacement*

**As identified in the second follow-up survey:**

- *depression*
- *gout in should and arm; fall resulting in collapsed lung*
- *Stomach ulcer caused due to medication interaction - corrected by changing med combination*

**As identified in the third follow-up survey: None**

**As identified in the fourth follow-up survey:**

- *Chronic abdominal wound is currently infected – copious amounts of putrid drainage*

**Overall, how would you rate the physical health of the person you are caring for? Please select the one word that best describes how you would rate your care-receiver's health.**

Site	Poor	Fair	Good	Very Good	Excellent	Mean (SD)
<b>First Survey</b>						
Sudbury/ Timmins (N = 19)	15.8% (3)	26.3% (5)	21.0% (4)	31.6% (6)	0	2.72 (1.1) N = 18
Kingston (N = 24)	0	20.8% (5)	45.8% (11)	25.0% (6)	8.3% (2)	3.19 (.92) N = 24
Ottawa (N = 24)	4.2% (1)	37.5% (9)	33.3% (8)	20.8% (5)	4.2% (1)	2.83 (.96) N = 24
Grey Bruce/ Huron/ Perth (N = 25)	4.0% (1)	32.0% (8)	28.0% (7)	24.0% (6)	12.0% (3)	3.06 (1.1) N = 25
<b>Across all sites (N = 92)</b>	5.4% (5)	29.3% (27)	32.6% (30)	25.0% (23)	6.5% (6)	2.97 (1.0) N = 91

Site	1 Much worse now	2	3 About the same	4	5 Much better now
<b>Second Survey</b>					
Sudbury/ Timmins (N = 19)	10.5%(2)	26.3%(5)	10.5%(2)	0	5.3% (1)
Kingston (N = 24)	0	20.8%(5)	45.8%(11)	45.8%(11)	12.5%(3)

<b>Site</b>	<b>1 Much worse now</b>	<b>2</b>	<b>3 About the same</b>	<b>4</b>	<b>5 Much better now</b>
Ottawa (N = 24)	8.3%(2)	16.6%(4)	37.5%(9)	0	4.2%(1)
Grey Bruce/ Huron/ Perth (N = 25)	16.0%(4)	36.0%(9)	24.0%(6)	0	4.0%(1)
<b>Across all sites (N = 92)</b>	8.7% (8)	25.0%(23)	30.4%(28)	1.1%(1)	6.5%(6)
<b>Third Survey</b>					
Sudbury/ Timmins (N = 10)	0	0	30.0%(3)	0	0
Kingston (N = 20)	10.0%(2)	10.0%(2)	35.5%(7)	10.0%(2)	0
Ottawa (N = 17)	0	11.8%(2)	23.5%(4)	11.8%(2)	0
Grey Bruce/ Huron/ Perth (N = 20)	5.0%(1)	25.0%(5)	50.0%(10)	5.0%(1)	0
<b>Across all sites (N = 67)</b>	4.5%(3)	13.4%(9)	35.8%(24)	7.5%(5)	0
<b>Fourth Survey</b>					
Sudbury/ Timmins (N = 3)	0	0	0	0	33.3%(1)
Kingston (N = 14)	7.1%(1)	14.3%(2)	29.4%(5)	7.1%(1)	0
Ottawa (N = 8)	12.5%(1)	12.5%(1)	12.5%(1)	0	0
Grey Bruce/ Huron/ Perth (N = 16)	6.3%(1)	6.3%(1)	18.8%(3)	6.3%(1)	0
<b>Across all sites (N = 41)</b>	7.3%(3)	9.8%(4)	9.8%(9)	4.9%(2)	2.4%(1)
<b>Fifth Survey</b>					
Sudbury/ Timmins (N = 0)	0	0	0	0	0
Kingston (N = 2)	0	100%(2)	0	0	0
Ottawa (N = 0)	0	0	0	0	0
Grey Bruce/ Huron/ Perth (N = 0)	0	0	0	0	0
<b>Across all sites (N = 2)</b>	0	100% (2)	0	0	0

## GENERAL INFORMATION

**How knowledgeable are you about the diagnosis (Alzheimer Disease or a related dementia) that the person you are caring for has? (5-point scale; 1 = not at all knowledgeable, 5 = extremely knowledgeable)**

Site	Mean (SD)	Range
<b>First Survey</b>		
Sudbury/ Timmins (N = 17)	2.91 (1.15)	1 – 5
Kingston (N = 24)	3.19 (1.19)	1 – 5
Ottawa (N = 24)	3.00 (.75)	1 – 4
Grey Bruce/ Huron/ Perth (N = 25)	2.96 (.90)	1.5 – 5
<b>Across all sites (N = 90)</b>	3.01 (.99)	1 – 5

Site	1 Less knowledgeable now	2	3 About the same	4	5 More knowledgeable now
<b>Second Survey</b>					
Sudbury/ Timmins (N = 19)	0	0	21.1%(4)	5.3%(1)	26.3%(5)
Kingston (N = 24)	0	0	20.8%(5)	29.2%(7)	16.6%(4)
Ottawa (N = 24)	0	0	12.5%(3)	12.5%(3)	45.8%(11)
Grey Bruce/ Huron/ Perth (N = 25)	0	0	4.0%(1)	36.0%(9)	40.0%(10)
<b>Across all sites (N = 92)</b>	0	0	14.1%(13)	21.7%(20)	37.0%(34)
<b>Third Survey</b>					
Sudbury/ Timmins (N = 10)	0	0	10.0%(1)	20.0%(2)	0
Kingston (N = 20)	0	0	35.0%(7)	15.0%(3)	15.0%(3)
Ottawa (N = 17)	0	0	5.9% (1)	11.8%(2)	29.4%(5)
Grey Bruce/ Huron/ Perth (N = 20)	0	0	10.0%(2)	25.0%(5)	50.0%(10)
<b>Across all sites (N = 67)</b>	0	0	16.4%(11)	17.9%(12)	26.8%(18)
<b>Fourth Survey</b>					
Sudbury/ Timmins (N =	0	0	0	0	0

<b>Site</b>	<b>1 Less knowledgeable now</b>	<b>2</b>	<b>3 About the same</b>	<b>4</b>	<b>5 More knowledgeable now</b>
3)					
Kingston (N = 14)	0	0	28.6%(4)	21.4%(3)	14.3%(2)
Ottawa (N = 8)	0	0	12.5%(1)	12.5%(1)	12.5%(1)
Grey Bruce/ Huron/ Perth (N = 16)	0	0	6.3%(1)	12.5%(2)	18.8%(3)
<b>Across all sites (N = 41)</b>	0	0	14.6%(6)	14.6%(6)	14.6%(6)
<b>Fifth Survey</b>					
Sudbury/ Timmins (N = 0)	0	0	0	0	0
Kingston (N = 2)	0	0	50.0%(1)	0	50.0%(1)
Ottawa (N = 0)	0	0	0	0	0
Grey Bruce/ Huron/ Perth (N = 0)	0	0	0	0	0
<b>Across all sites (N = 2)</b>	0	0	50.0%(1)	0	%(1)

#### BY REFERRAL STATUS

<b>Site</b>	<b>Mean (SD)</b>	<b>Range</b>
<b>First Survey</b>		
Self-Referred (N = 39)	3.0 (.97)	1 – 5
Referred via First Link (N = 39)	3.0 (1.0)	1 - 5

<b>Site</b>	<b>1 Less knowledgeable now</b>	<b>2</b>	<b>3 About the same</b>	<b>4</b>	<b>5 More knowledgeable now</b>
<b>Second Survey</b>					
Self-Referred (N = 28)	0	0	10.7% (3)	35.7% (10)	53.6% (15)
Referred via First Link (N = 30)	0	0	26.7% (8)	23.3% (7)	50.0% (15)
<b>Third Survey</b>					
Self-Referred (N = 21)	0	0	23.8% (5)	33.3% (7)	42.9% (9)
Referred via First Link (N = 15)	0	0	33.3% (5)	26.7% (4)	40.0% (6)
<b>Fourth Survey</b>					

Site	1 Less knowledgeable now	2	3 About the same	4	5 More knowledgeable now
Self-Referred (N = 10)	0	0	40.0% (4)	30.0% (3)	30.0% (3)
Referred via First Link (N = 9)	0	0	22.2% (2)	33.3% (3)	22.2% (2)
<b>Fifth Survey</b>					
Self-Referred (N = 2)	0	0	50.0% (1)	50.0% (1)	0
Referred via First Link (N = 0)	0	0	0	0	0

**How familiar are you with the community resources related to dementia that are available to you and your care-receiver?** (5-point scale; 1 = not at all familiar, 5 = extremely familiar)

Site	Mean (SD)	Range
<b>First Survey</b>		
Sudbury/ Timmins (N = 19)	2.90 (1.3)	1 – 5
Kingston (N = 23)	3.00 (1.3)	1 – 5
Ottawa (N = 24)	2.54 (.72)	1 – 4
Grey Bruce/ Huron/ Perth (N = 25)	3.20 (1.1)	1 – 5
<b>Across all sites (N = 91)</b>	2.91 (1.1)	1 – 5

Site	1 Less familiar now	2	3 About the same	4	5 More familiar now
<b>Second Survey</b>					
Sudbury/ Timmins (N = 19)	0	0	21.1%(4)	15.8%(3)	15.8%(3)
Kingston (N = 24)	0	0	20.8%(5)	29.2%(7)	33.3%(8)
Ottawa (N = 24)	0	0	0	16.7%(4)	54.2%(13)
Grey Bruce/ Huron/ Perth (N = 25)	0	0	12.0%(3)	16.0%(4)	52.0%(13)
<b>Across all sites (N = 92)</b>	0	0	13.0%(12)	19.6%(18)	40.2%(37)
<b>Third Survey</b>					
Sudbury/ Timmins (N = 10)	0	0	20.0%(2)	10.0%(1)	0



<b>Site</b>	<b>1 Less familiar now</b>	<b>2</b>	<b>3 About the same</b>	<b>4</b>	<b>5 More familiar now</b>
Kingston (N = 20)	0	0	25.0%(5)	20.0%(4)	10.0%(2)
Ottawa (N = 17)	0	0	5.9%(1)	17.6%(3)	23.5%(4)
Grey Bruce/ Huron/ Perth (N = 20)	0	0	15.0%(3)	25.0%(5)	45.0%(9)
<b>Across all sites (N = 67)</b>	0	0	16.4%(11)	19.4%(13)	22.4%(15)
<b>Fourth Survey</b>					
Sudbury/ Timmins (N = 3)	0	0	0	0	0
Kingston (N = 14)	0	0	42.9%(6)	14.3%(2)	7.1%(1)
Ottawa (N = 8)	0	0	25.0%(2)	12.5%(1)	0
Grey Bruce/ Huron/ Perth (N = 16)	0	0	18.8%(3)	6.3%(1)	12.6%(2)
<b>Across all sites (N = 41)</b>	0	0	26.8%(11)	9.8%(4)	7.3%(3)
<b>Fifth Survey</b>					
Sudbury/ Timmins (N = 0)	0	0	0	0	0
Kingston (N = 2)	0	0	100%(2)	0	0
Ottawa (N = 0)	0	0	0	0	0
Grey Bruce/ Huron/ Perth (N = 0)	0	0	0	0	0
<b>Across all sites (N = 2)</b>	0	0	0	0	0

#### BY REFERRAL STATUS

<b>Site</b>	<b>Mean (SD)</b>	<b>Range</b>
<b>First Survey</b>		
Self-Referred (N = 38)	3.1 (1.1)	1 - 5
Referred via First Link (N = 40)	2.8 (1.1)	1 - 5

Site	1 Less familiar now	2	3 About the same	4	5 More familiar now
<b>Second Survey</b>					
Self-Referred (N = 28)	0	0	17.9% (5)	17.9% (5)	64.3% (18)
Referred via First Link (N = 30)	0	0	13.3% (4)	40.0% (12)	46.7% (14)
<b>Third Survey</b>					
Self-Referred (N = 21)	0	0	23.8% (5)	28.5% (6)	38.1% (8)
Referred via First Link (N = 15)	0	0	33.3% (5)	33.3% (5)	33.3% (5)
<b>Fourth Survey</b>					
Self-Referred (N = 10)	0	0	80.0% (8)	10.0% (1)	10.0% (1)
Referred via First Link (N = 9)	0	0	33.3% (3)	22.2% (2)	22.2% (2)
<b>Fifth Survey</b>					
Self-Referred (N = 2)	0	0	100% (2)	0	0
Referred via First Link (N = 0)	0	0	0	0	0

*The Coping Effectiveness Scale* (Gottlieb & Rooney, 2004)

Site	Mean (SD) <sup>16</sup>	Range
<b>First Survey</b>		
Sudbury/ Timmins (N = 18)	20.67 (2.7)	16 – 26
Kingston (N = 22)	21.57 (2.9)	14 – 28
Ottawa (N = 24)	22.04 (2.2)	19 – 27
Grey Bruce/ Huron/ Perth (N = 25)	20.96 (2.45)	16 – 26
<b>Across all sites (N = 89)</b>	21.34 (2.6)	14 – 28
<b>Second Survey</b>		
Sudbury/ Timmins (N = 10)	21.5 (3.3)	17 – 27
Kingston (N = 20)	20.9 (2.7)	15 – 25
Ottawa (N = 17)	22.8 (2.8)	19 – 28
Grey Bruce/ Huron/ Perth (N = 19)	20.9 (2.8)	17 - 27
<b>Across all sites (N = 66)</b>	21.5 (2.9)	15 - 28
<b>Third Survey</b>		
Sudbury/ Timmins (N = 3)	21.3 (2.08)	19 – 23
Kingston (N = 13)	21.3 (1.9)	19 – 25
Ottawa (N = 8)	22.8 (.84)	22 – 24
Grey Bruce/ Huron/ Perth (N = 17)	21.2 (3.2)	15 – 29
<b>Across all sites (N = 41)</b>	21.6 (2.5)	15 - 29
<b>Fourth Survey</b>		
Sudbury/ Timmins (N = 0)	N/A	N/A
Kingston (N = 8)	21.8 (2.6)	17 – 26
Ottawa (N = 3)	20.0 (1.0)	19 – 21
Grey Bruce/ Huron/ Perth (N = 6)	20.7 (3.1)	18 – 26
<b>Across all sites (N = 17)</b>	21.1 (2.6)	17 – 26
<b>Fifth Survey</b>		
Sudbury/ Timmins (N = 0)	N/A	N/A
Kingston (N = 2)	20.00 (2.8)	18 - 22
Ottawa (N = 0)	N/A	N/A
Grey Bruce/ Huron/ Perth (N = 0)	N/A	N/A
<b>Across all sites (N = 2)</b>	20.00 (2.8)	18 - 22

<sup>16</sup> A total score is obtained by summing the items (after reverse scoring the items reflecting coping ineffectiveness). Higher scores reflect coping effectiveness. For the first survey, there were 2 stances in which one of the scale items was missing values, in these cases the average score of completed items was used to score the missing items.

*The Coping Effectiveness Scale: By Referral Status*

Site	Mean (SD)	Range
<b>First Survey</b>		
Self-Referred (N = 38)	21.16 (2.5)	16 – 28
Referred via First Link (N = 39)	21.50 (2.7)	14 – 27
<b>Second Survey</b>		
Self-Referred (N = 28)	21.75 (3.1)	16 – 27
Referred via First Link (N = 29)	21.21 (2.9)	15 - 28
<b>Third Survey</b>		
Self-Referred (N = 21)	21.62 (3.0)	15 – 29
Referred via First Link (N = 15)	21.40 (1.7)	19- 24
<b>Fourth Survey</b>		
Self-Referred (N = 9)	20.56 (3.3)	17 – 26
Referred via First Link (N = 7)	22.00 (1.2)	20 – 23
<b>Fifth Survey</b>		
Self-Referred (N = 2)	20.00 (2.8)	18 – 22
Referred via First Link (N = 0)	n/a	n/a

**Caregiver Burden Inventory (N = 44)**

Subscale	Mean (SD)	Range
Time Dependence	9.8 (6.1)	0 – 20
Developmental Burden	9.9 (6.5)	0 – 20
Physical Burden	5.9 (5.0)	0 – 16
Social Burden	6.2 (5.8)	0 – 19
Emotional Burden	3.9 (3.8)	0 – 18
<b>Total Score</b>	<b>35.1 (22.9)</b>	<b>0 – 86</b>

### Caregiver Burden Inventory By Referral Status:

Subscale	Self-Referred Mean (SD) N = 17	Referred via First Link Mean (SD) N= 23
Time Dependence	11.7 (6.8)	8.0 (5.4)
Developmental Burden	11.8 (6.9)	8.0 (6.2)
Physical Burden	7.9 (4.3)	4.2 (4.8)
Social Burden	5.6 (5.9)	4.7 (5.7)
Emotional Burden	4.5 (4.6)	3.7 (3.3)
<b>Total Score</b>	<b>44.8 (24.1)</b>	<b>28.6 (21.8)</b>

*Differences by referral status* (ANOVA): Those referred via First Link have a significantly lower total score (M = 28.6, SD = 21.8) on the Caregiver Burden Inventory than those self-referred (M = 44.8, SD = 24.1),  $F(1,37) = 4.77$ ,  $p < .05$ .

**Overall, how confident do you feel in your ability to manage your role as a caregiver to this individual?** (5-point scale; 1 = not at all confident, 5 = extremely confident)

Site	Mean (SD)	Range
<b>First Survey</b>		
Sudbury/ Timmins (N = 19)	3.36 (1.0)	1 – 5
Kingston (N = 24)	3.67 (.87)	2 – 5
Ottawa (N = 24)	3.40 (.87)	1 – 5
Grey Bruce/ Huron/ Perth (N = 24)	3.33 (.56)	2 – 4
<b>Across all sites (N = 91)</b>	<b>3.45 (.83)</b>	<b>1 – 5</b>

Site	1 Less confident now	2	3 About the same	4	5 More confident now
<b>Second Survey</b>					
Sudbury/ Timmins (N = 19)	0	5.3%(1)	15.8%(3)	10.5%(2)	21.1%(4)
Kingston (N = 24)	4.2%(1)	0	29.2%(7)	29.2%(7)	16.7%(4)
Ottawa (N = 24)	0	12.5%(3)	8.3%(2)	12.5%(3)	37.5%(9)
Grey Bruce/ Huron/ Perth (N = 25)	0	12.9%(3)	36.0%(9)	16.0%(4)	12.0%(3)
<b>Across all sites (N = 92)</b>	<b>1.1%(1)</b>	<b>7.6%(7)</b>	<b>22.8%(21)</b>	<b>17.4%(16)</b>	<b>21.7%(20)</b>

Site	1 Less confident now	2	3 About the same	4	5 More confident now
<b>Third Survey</b>					
Sudbury/ Timmins (N = 10)	0	0	20.0%(2)	0	10.0%(1)
Kingston (N = 20)	0	5.0%(1)	25.0%(5)	30.0%(6)	5.0%(1)
Ottawa (N = 17)	0	0	11.8%(2)	17.6%(3)	17.6%(3)
Grey Bruce/ Huron/ Perth (N = 20)	10.0%(2)	0	20.0%(4)	35.0%(7)	20.0%(4)
<b>Across all sites (N = 67)</b>	3.0%(2)	1.5%(1)	19.4%(13)	23.9%(16)	13.4%(9)
<b>Fourth Survey</b>					
Sudbury/ Timmins (N = 3)	0	0	0	0	33.3% (1)
Kingston (N = 14)	0	0	28.6%(4)	21.4%(3)	0
Ottawa (N = 8)	0	0	25.0%(2)	0	12.5%(1)
Grey Bruce/ Huron/ Perth (N = 16)	0	6.3%(1)	12.5%(2)	12.5%(2)	6.3%(1)
<b>Across all sites (N = 41)</b>	0	2.4%(1)	19.5%(8)	19.5%(8)	7.3%(3)
<b>Fifth Survey</b>					
Sudbury/ Timmins (N = 0)	0	0	0	0	0
Kingston (N = 2)	0	0	100% (2)	0	0
Ottawa (N = 0)	0	0	0	0	0
Grey Bruce/ Huron/ Perth (N = 0)	0	0	0	0	0
<b>Across all sites (N = 2)</b>	0	0	100% (2)	0	0

#### BY REFERRAL STATUS

Site	Mean (SD)	Range
<b>First Survey</b>		
Self-Referred (N = 38)	3.40 (.92)	1 – 5
Referred via First Link (N = 40)	3.41 (1.0)	1 - 5

Site	1 Less confident now	2	3 About the same	4	5 More confident now
<b>Second Survey</b>					
Self-Referred (N = 28)	0	7.1% (2)	46.4% (13)	17.9% (5)	28.6% (8)
Referred via First Link (N = 30)	3.3% (1)	13.3% (4)	16.7% (5)	26.7% (8)	33.3% (10)
<b>Third Survey</b>					
Self-Referred (N = 21)	9.5% (2)	0	28.6% (6)	33.3% (7)	28.6% (6)
Referred via First Link (N = 15)	0	6.7% (1)	40.0% (6)	40.0% (6)	13.3% (2)
<b>Fourth Survey</b>					
Self-Referred (N = 10)	0	10.0% (1)	50.0% (5)	20.0% (2)	10.0% (1)
Referred via First Link (N = 9)	0	% ()	33.3% (3)	33.3% (3)	11.1% (1)
<b>Fifth Survey</b>					
Self-Referred (N = 2)	0	0	100% (2)	0	0
Referred via First Link (N = 0)	0	0	0	0	0

**Overall, how would you rate your current ability to manage your role as a caregiver to this individual?** (5-point scale; 1 = not at all capable, 5 = extremely capable)

Site	Mean (SD)	Range
<b>First Survey</b>		
Sudbury/ Timmins (N = 19)	3.68 (1.1)	1 – 5
Kingston (N = 24)	3.90 (.81)	2 – 5
Ottawa (N = 24)	3.50 (.83)	1 – 5
Grey Bruce/ Huron/ Perth (N = 24)	3.17 (.64)	2 – 4
<b>Across all sites (N = 91)</b>	3.56 (.86)	1 – 5

**Differences between sites:**  $F(3, 87) = 3.26, p < .05$ ; Post Hoc tests (Tukey HSD) confirm significant differences in means between Kingston (3.90) and Grey Bruce (3.17).

Site	1 Less capable now	2	3 About the same	4	5 More capable now
<b>Second Survey</b>					
Sudbury/ Timmins (N = 19)	5.3%(1)	0	15.8%(3)	5.3%(1)	26.3%(5)
Kingston (N = 24)	0	4.2%(1)	25.0%(6)	25.0%(6)	20.8%(5)
Ottawa (N = 24)	4.2%(1)	4.2%(1)	8.3%(2)	25.0%(6)	29.2%(7)
Grey Bruce/ Huron/ Perth (N = 25)	4.0%(1)	12.0%(3)	24.0%(6)	28%(7)	12.0%(3)
<b>Across all sites (N = 92)</b>	3.4%(3)	5.4%(5)	18.5%(17)	21.7%(20)	21.7%(20)
<b>Third Survey</b>					
Sudbury/ Timmins (N = 10)	10.0%(1)	0	10.0%(1)	0	10.0%(1)
Kingston (N = 20)	5.0%(1)	0	20.0%(4)	25.0%(7)	5.0%(1)
Ottawa (N = 17)	0	0	11.8%(2)	17.6%(3)	17.6%(3)
Grey Bruce/ Huron/ Perth (N = 20)	10.0%(2)	0	15.0%(3)	40.0%(8)	15.0%(3)
<b>Across all sites (N = 67)</b>	6.0%(4)	0	14.9%(10)	26.9%(18)	11.9%(8)
<b>Fourth Survey</b>					
Sudbury/ Timmins (N = 3)	0	0	0	0	33.3%(1)
Kingston (N = 14)	0	0	21.4%(3)	21.4%(3)	7.1%(1)
Ottawa (N = 8)	0	0	25.0%(2)	0	12.5%(1)
Grey Bruce/ Huron/ Perth (N = 16)	0	0	18.8%(3)	12.5%(2)	6.3%(1)
<b>Across all sites (N = 41)</b>	0	0	19.5%(8)	12.2%(5)	9.8%(4)
<b>Fifth Survey</b>					
Sudbury/ Timmins (N = 0)	0	0	0	0	0
Kingston (N = 2)	0	0	100% (2)	0	0
Ottawa (N = 0)	0	0	0	0	0
Grey Bruce/ Huron/ Perth (N = 0)	0	0	0	0	0
<b>Across all sites (N = 2)</b>	0	0	100% (2)	0	0



## BY REFERRAL STATUS

Site	Mean (SD)	Range
<b>First Survey</b>		
Self-Referred (N = 38)	3.38 (.98)	1 – 5
Referred via First Link (N = 40)	3.70 (1.0)	1 - 5

Site	less capable now	2	3 About the same	4	5 More capable now
<b>Second Survey</b>					
Self-Referred (N = 28)	3.6% (1)	7.1% (2)	32.1% (9)	25.0% (7)	28.6% (8)
Referred via First Link (N = 30)	6.7% (2)	6.7% (2)	16.7% (5)	30.0% (9)	36.7% (11)
<b>Third Survey</b>					
Self-Referred (N = 21)	9.5% (2)	0	19.0% (4)	42.9% (9)	23.8% (5)
Referred via First Link (N = 15)	13.3% (2)	0	33.3% (5)	46.7% (7)	6.7% (1)
<b>Fourth Survey</b>					
Self-Referred (N = 10)	0	0	60.0% (6)	20.0% (2)	10.0% (1)
Referred via First Link (N = 9)	0	0	22.2% (2)	33.3% (3)	22.2% (2)
<b>Fifth Survey</b>					
Self-Referred (N = 2)	0	0	100% (2)	0	0
Referred via First Link (N = 0)	0	0	0	0	0

Overall, how stressed do you feel by this individual's care (i.e., stress due to time, energy, demands or behaviours)? (6-point scale: 1 = no stress at all, 6 = the most stress I've ever experienced related to this person).

Site	Mean (SD)	Range
<b>First Survey*</b>		
Sudbury/ Timmins (N = 9)	5.56 (.73)	4 – 6
Kingston (N = 5)	5.00 (1.2)	3 – 6
Ottawa (N = 15)	4.40 (1.4)	3 – 6
Grey Bruce/ Huron/ Perth (N = 14)	4.21 (1.3)	2 – 6
<b>Across all sites (N = 43)</b>	4.65 (1.3)	2 – 6

<b>Second Survey</b>		
Sudbury/ Timmins (N = 10)	4.80 (1.3)	3 – 6
Kingston (N = 18)	4.39 (1.3)	2 – 6
Ottawa (N = 17)	4.24 (1.4)	2 – 6
Grey Bruce/ Huron/ Perth (N = 20)	4.65 (.99)	3 – 6
<b>Across all sites (N = 65)</b>	4.49 (1.3)	2 – 6

Site	Mean (SD)	Range
<b>Third Survey</b>		
Sudbury/ Timmins (N = 3)	4.00 (1.0)	3 – 5
Kingston (N = 13)	4.15 (1.2)	2 – 6
Ottawa (N = 8)	4.38 (.92)	3 – 6
Grey Bruce/ Huron/ Perth (N = 17)	4.06 (1.3)	2 – 6
<b>Across all sites (N = 41)</b>	4.15 (1.2)	2 – 6
<b>Fourth Survey</b>		
Sudbury/ Timmins (N = 1)	2.00	2
Kingston (N = 7)	3.00 (1.2)	2 – 5
Ottawa (N = 3)	4.00 (1.0)	3 – 5
Grey Bruce/ Huron/ Perth (N = 6)	3.67 (1.4)	2 – 6
<b>Across all sites (N = 17)</b>	3.35 (1.2)	2 – 5
<b>Fifth Survey</b>		
Sudbury/ Timmins (N = 0)	N/A	N/A
Kingston (N = 2)	5.00 (.00)	5
Ottawa (N = 0)	N/A	N/A
Grey Bruce/ Huron/ Perth (N = 0)	N/A	N/A
<b>Across all sites (N = 2)</b>	5.00 (.00)	5

\*The response rate to this question in the first survey is low because this question was added at a later date (October 2008).

#### ***Paired t-tests - Differences across survey times***

Survey	Mean (SD)	t-test
Survey 2 (Follow-up 1) (N = 41)	4.32 (1.1)	t(40) = .85, p = n.s.
Survey 3 (Follow-up 2) (N = 41)	4.15 (1.2)	
Survey 2 (Follow-up 1) (N = 17)	4.35 (1.2)	t(16) = 3.52, p = .003
Survey 4 (Follow-up 3) (N = 17)	3.35 (1.2)	
Survey 3 (Follow-up 2) (N = 17)	3.77 (1.3)	t(16) = 1.38, p = n.s.
Survey 4 (Follow-up 3) (N = 17)	3.35 (1.2)	

**BY REFERRAL STATUS**

Site	Mean (SD)	Range
<b>First Survey</b>		
Self-Referred (N = 38)	3.38 (.98)	1 – 5
Referred via First Link (N = 40)	3.70 (1.0)	1 - 5
<b>Total (N = 2)</b>	<b>3.53 (.76)</b>	<b>1 – 5</b>

Site	less capable now	2	3 About the same	4	5 More capable now
<b>Second Survey</b>					
Self-Referred (N = 28)	3.6% (1)	7.1% (2)	42.9% (9)	33.3% (7)	38.1% (8)
Referred via First Link (N = 30)	6.7% (2)	6.7% (2)	16.6% (5)	30.0% (9)	36.7% (11)
<b>Third Survey</b>					
Self-Referred (N = 21)	9.5% (2)	0	19.0% (4)	42.9% (9)	23.8% (5)
Referred via First Link (N = 15)	13.3% (2)	0	33.3% (5)	46.7% (7)	6.7% (1)
<b>Fourth Survey</b>					
Self-Referred (N = 10)	0	0	60.0% (6)	30.0% (2)	10.0% (1)
Referred via First Link (N = 9)	0	0	22.2% (2)	33.3% (3)	22.2% (2)
<b>Fifth Survey</b>					
Self-Referred (N = 2)	0	0	100% (2)	0	0
Referred via First Link (N = 0)	0	0	0	0	0

## QUESTIONS THAT APPEAR ONLY IN THE FOLLOW-UP SURVEYS

**In the past six months have you received any written material about Alzheimer disease and related dementias from First Link or your local Alzheimer Society chapter?**

Site	No	I don't recall	Yes
<b>Second Survey</b>			
Sudbury/ Timmins (N = 19)	5.3%(1)	10.5%(2)	36.8%(7)
Kingston (N = 24)	0	8.3%(2)	70.8%(17)
Ottawa (N = 24)	4.2%(1)	8.3%(2)	58.3%(14)
Grey Bruce/ Huron/ Perth (N = 25)	4.0%(1)	16.0%(4)	60.0%(15)
<b>Across all sites (N = 92)</b>	3.2%(3)	10.9%(10)	57.6%(53)
<b>Third Survey</b>			
Sudbury/ Timmins (N = 10)	10.0%(1)	0	20.0%(2)
Kingston (N = 20)	5.0%(1)	10.0%(2)	50.0%(10)
Ottawa (N = 17)	5.9% (1)	0	41.2%(7)
Grey Bruce/ Huron/ Perth (N = 20)	10.0%(2)	20.0%(4)	55.0%(11)
<b>Across all sites (N = 67)</b>	6.0%(4)	9.0%(6)	44.8%(30)
<b>Fourth Survey</b>			
Sudbury/ Timmins (N = 3)	33.3%(1)	0	0
Kingston (N = 14)	14.3%(2)	0	35.7%(5)
Ottawa (N = 8)	0	0	37.5% (3)
Grey Bruce/ Huron/ Perth (N = 16)	12.5%(2)	0	25.0% (4)
<b>Across all sites (N = 41)</b>	12.2%(5)	0	29.3%(12)
<b>Fifth Survey</b>			
Sudbury/ Timmins (N = 0)	0	0	0
Kingston (N = 2)	100% (2)	0	0
Ottawa (N = 0)	0	0	0
Grey Bruce/ Huron/ Perth (N = 0)	0	0	0
<b>Across all sites (N = 2)</b>	100%(2)	0	0

## BY REFERRAL STATUS

Site	No	I don't recall	Yes
<b>Second Survey</b>			
Self-Referred (N = 28)	0	14.3% (4)	82.1% (23)
Referred via First Link (N = 30)	6.7% (2)	13.3% (4)	60.0% (24)
<b>Third Survey</b>			
Self-Referred (N = 21)	14.3% (3)	14.3% (3)	71.4% (15)
Referred via First Link (N = 15)	6.7% (1)	6.7% (1)	86.7% (113)
<b>Fourth Survey</b>			
Self-Referred (N = 10)	40.0% (4)	0	50.0% (5)
Referred via First Link (N = 9)	11.1% (1)	0	66.7% (6)
<b>Fifth Survey</b>			
Self-Referred (N = 2)	100% (2)	0	0
Referred via First Link (N = 0)	0	0	0

If yes, how helpful was this information to you? (5-point scale; 1 = not at all, 5 = extremely helpful)

Site	Mean (SD)	Range
<b>Second Survey</b>		
Sudbury/ Timmins (N = 7)	3.86 (1.1)	2 – 5
Kingston (N = 16)	3.50 (1.2)	2 – 5
Ottawa (N = 14)	3.67 (.61)	3 – 5
Grey Bruce/ Huron/ Perth (N = 15)	3.71 (.82)	2 – 5
<b>Across all sites (N = 52)</b>	3.65 (.93)	2 – 5
<b>Third Survey</b>		
Sudbury/ Timmins (N = 2)	2.50 (2.1)	1 – 4
Kingston (N = 10)	3.10 (1.3)	1 – 5
Ottawa (N = 7)	3.43 (.79)	2 – 4
Grey Bruce/ Huron/ Perth (N = 11)	3.54 (.52)	3 – 4
<b>Across all sites (N = 30)</b>	3.30 (.99)	1 – 5

Site	Mean (SD)	Range
<b>Fourth Survey</b>		
Sudbury/ Timmins (N = 0)	N/A	N/A
Kingston (N = 5)	3.80 (1.3)	1 – 5
Ottawa (N = 3)	3.00 (1.0)	2 – 4
Grey Bruce/ Huron/ Perth (N = 4)	3.25 (.50)	3 - 4
<b>Across all sites (N = 12)</b>	3.42 (.99)	1 – 5
<b>Fifth Survey</b>		
Sudbury/ Timmins (N = 0)	N/A	N/A
Kingston (N = 0)	N/A	N/A
Ottawa (N = 0)	N/A	N/A
Grey Bruce/ Huron/ Perth (N = 0)	N/A	N/A
<b>Across all sites (N = 0)</b>	N/A	N/A

N/A = not applicable (no values)

## BY REFERRAL STATUS

Site	Mean (SD)	Range
<b>Second Survey</b>		
Self-Referred (N = 23)	3.48 (.95)	2 – 5
Referred via First Link (N = 23)	3.78 (.95)	2 – 5
<b>Third Survey</b>		
Self-Referred (N = 15)	3.33 (.90)	1 – 4
Referred via First Link (N = 13)	3.23 (1.2)	1 – 5
<b>Fourth Survey</b>		
Self-Referred (N = 5)	3.00 (.71)	2 – 4
Referred via First Link (N = 6)	3.83 (1.2)	2 – 5
<b>Fifth Survey</b>		
Self-Referred (N = 2)	n/a	n/a
Referred via First Link (N = 0)		

**In the past six months did First Link or your local Alzheimer Society Chapter tell you about or send you information about community resources or services that are available to you?**

<b>Site</b>	<b>No – not given information</b>	<b>No – received information, but did not contact them</b>	<b>I don't recall</b>	<b>Yes</b>
<b>Second Survey</b>				
Sudbury/ Timmins (N = 19)	0	5.3%(1)	5.3%(1)	42.1%(8)
Kingston (N = 24)	4.2%(1)	4.7%(1)	8.3%(2)	62.5%(15)
Ottawa (N = 24)	0	8.3%(2)	4.2%(1)	58.3%(14)
Grey Bruce/ Huron/ Perth (N = 25)	4.0%(1)	4.0%(1)	4.0%(1)	68.0%(17)
<b>Across all sites (N = 92)</b>	21.7%(2)	5.4%(5)	5.4%(5)	58.7%(54)
<b>Third Survey</b>				
Sudbury/ Timmins (N = 10)	0	20.0%(2)	0	5.3%(1)
Kingston (N = 20)	5.0%(1)	0	10.0%(2)	45.0%(9)
Ottawa (N = 17)	11.8%(2)	0	5.9%(1)	29.4%(5)
Grey Bruce/ Huron/ Perth (N = 20)	15.0%(3)	0	15.0%(3)	55.0%(11)
<b>Across all sites (N = 67)</b>	9.0%(6)	3.0%(2)	9.0%(6)	38.8%(26)
<b>Fourth Survey</b>				
Sudbury/ Timmins (N = 3)	0	33.3%(1)	0	0
Kingston (N = 14)	21.4%(3)	14.3%(2)	0	21.4%(3)
Ottawa (N = 8)	25.0%(2)	0	12.5%(1)	0
Grey Bruce/ Huron/ Perth (N = 16)	18.8%(3)	0	0	18.8%(3)
<b>Across all sites (N = 41)</b>	19.5%(8)	7.3%(3)	2.4%(1)	14.6%(6)
<b>Fifth Survey</b>				
Sudbury/ Timmins (N = 0)	0	0	0	0
Kingston (N = 2)	100% (2)	0	0	0
Ottawa (N = 0)	0	0	0	0
Grey Bruce/ Huron/ Perth (N = 0)	0	0	0	0
<b>Across all sites (N = 2)</b>	100%(2)	0	0	0

## BY REFERRAL STATUS

Site	No – not given information	No – received information, but did not contact them	I don't recall	Yes
<b>Second Survey</b>				
Self-Referred (N = 28)	0	3.6% (1)	10.7% (3)	82.1% (23)
Referred via First Link (N = 30)	3.3% (1)	10.0% (3)	6.7% (2)	80.0% (24)
<b>Third Survey</b>				
Self-Referred (N = 21)	14.3% (3)	0	9.5% (2)	71.4% (15)
Referred via First Link (N = 15)	13.3% (2)	13.37% (21)	13.3% (21)	60.0% (9)
<b>Fourth Survey</b>				
Self-Referred (N = 10)	60.0% (6)	10.0% (1)	0	20.0% (2)
Referred via First Link (N = 9)	22.2% (2)	22.2% (2)	0	55.6% (4)
<b>Fifth Survey</b>				
Self-Referred (N = 2)	100.0% (2)	0	0	0
Referred via First Link (N = 0)	0	0	0	0

If yes, how helpful were these resources or services? (5-point scale; 1 = not at all, 5 = extremely helpful)

Site	Mean (SD)	Range
<b>Second Survey</b>		
Sudbury/ Timmins (N = 8)	3.48 (1.4)	1 – 5
Kingston (N = 14)	3.50 (1.16)	1 – 5
Ottawa (N = 14)	3.93 (.83)	2 – 5
Grey Bruce/ Huron/ Perth (N = 17)	3.65 (.79)	2 – 5
<b>Across all sites (N = 53)</b>	3.64 (1.00)	1 – 5
<b>Third Survey</b>		
Sudbury/ Timmins (N = 2)	2.50 (2.1)	1 – 4
Kingston (N = 10)	2.90 (1.29)	1 – 5
Ottawa (N = 7)	3.40 (.55)	3 – 4
Grey Bruce/ Huron/ Perth (N = 11)	3.64 (.67)	3 – 5
<b>Across all sites (N = 28)</b>	3.25 (1.0)	1 – 5



Site	Mean (SD)	Range
<b>Fourth Survey</b>		
Sudbury/ Timmins (N = 0)	N/A	N/A
Kingston (N = 4)	3.75 (1.3)	2 - 5
Ottawa (N = 0)	N/A	N/A
Grey Bruce/ Huron/ Perth (N = 3)	3.67 (.57)	3 – 4
<b>Across all sites (N = 7)</b>	3.7 (.95)	2 - 5
<b>Fifth Survey</b>		
Sudbury/ Timmins (N = 0)	N/A	N/A
Kingston (N = 0)	N/A	N/A
Ottawa (N = 0)	N/A	N/A
Grey Bruce/ Huron/ Perth (N = 0)	N/A	N/A
<b>Across all sites (N = 0)</b>	N/A	N/A

N/A = not applicable (no values)

#### BY REFERRAL STATUS

Site	Mean (SD)	Range
<b>Second Survey</b>		
Self-Referred (N = 23)	3.57 (.95)	1 – 5
Referred via First Link (N = 23)	3.78 (1.1)	2 – 5
<b>Third Survey</b>		
Self-Referred (N = 16)	3.31 (.95)	1 – 5
Referred via First Link (N = 10)	3.10 (1.3)	1 – 5
<b>Fourth Survey</b>		
Self-Referred (N = 3)	3.30 (1.0)	2 – 4
Referred via First Link (N = 4)	4.25 (.50)	4 – 5
<b>Fifth Survey</b>		
Self-Referred (N = 0)	n/a	
Referred via First Link (N = 0)	n/a	

N/A = not applicable (no values)

**In the past six months did First Link or your local Alzheimer Society Chapter tell you about or send you information about education or information sessions about Alzheimer disease and related dementias?**

<b>Site</b>	<b>No – not given information</b>	<b>No – received information, but did not contact them</b>	<b>I don't recall</b>	<b>Yes</b>
<b>Second Survey</b>				
Sudbury/ Timmins (N = 19)	5.3%(1)	5.3%(1)	0	42.1%(8)
Kingston (N = 24)	4.7%(1)	0	12.5%(3)	66.7%(16)
Ottawa (N = 24)	4.7%(1)	16.7%(4)	8.3%(2)	41.7%(10)
Grey Bruce/ Huron/ Perth (N = 25)	%(1)	%(1)	%(3)	%(15)
<b>Across all sites (N = 92)</b>	4.3%(4)	6.5%(6)	8.7%(8)	53.3%(49)
<b>Third Survey</b>				
Sudbury/ Timmins (N = 10)	10.0%(1)	0	0	20.0%(2)
Kingston (N = 20)	0	10.0%(2)	0	50.0%(10)
Ottawa (N = 17)	0	5.9%(1)	5.9%(1)	35.3%(6)
Grey Bruce/ Huron/ Perth (N = 20)	15.0%(3)	0	15.0%(3)	55.0%(11)
<b>Across all sites (N = 67)</b>	6.0%(4)	4.5%(3)	4.5%(4)	43.3%(29)
<b>Fourth Survey</b>				
Sudbury/ Timmins (N = 3)	0	33.3%(1)	0	0
Kingston (N = 14)	7.1%(1)	7.1%(1)	0	35.7%(5)
Ottawa (N = 8)	0	12.5%(1)	12.5%(1)	12.5%(1)
Grey Bruce/ Huron/ Perth (N = 16)	12.5%(2)	0	0	25.0%(4)
<b>Across all sites (N = 41)</b>	7.3%(3)	7.3%(3)	2.4%(1)	24.4%(10)
<b>Fifth Survey</b>				
Sudbury/ Timmins (N = 0)	0	0	0	0
Kingston (N = 2)	50.0% (1)	0	0	50.0(1)
Ottawa (N = 0)	0	0	0	0
Grey Bruce/ Huron/ Perth (N = 0)	0	0	0	0
<b>Across all sites (N = 2)</b>	50.0%(1)	0	0	50.0%(1)

## BY REFERRAL STATUS

Site	No – not given information	No – received information, but did not contact them	I don't recall	Yes
<b>Second Survey</b>				
Self-Referred (N = 28)	3.6% (1)	3.6% (1)	14.3% (4)	78.6% (22)
Referred via First Link (N = 30)	3.3% (1)	16.7% (5)	6.7% (2)	73.3% (22)
<b>Third Survey</b>				
Self-Referred (N = 21)	9.5% (2)	9.5% (2)	0	76.2% (16)
Referred via First Link (N = 15)	6.7% (1)	6.7% (1)	6.7% (1)	80.0% (12)
<b>Fourth Survey</b>				
Self-Referred (N = 10)	40.0% (4)	0	0	50.0% (5)
Referred via First Link (N = 9)	0	33.3% (3)	0	55.6% (5)
<b>Fifth Survey</b>				
Self-Referred (N = 2)	50.0% (1)	0	0	50.0% (1)
Referred via First Link (N = 0)	0	0	0	0

If yes, how helpful were these sessions? (5-point scale; 1 = not at all, 5 = extremely helpful)

Site	Mean (SD)	Range
<b>Second Survey</b>		
Sudbury/ Timmins (N = 7)	4.29 (.95)	3 – 5
Kingston (N = 13)	3.77 (1.6)	1 – 5
Ottawa (N = 11)	4.73 (.47)	4 – 5
Grey Bruce/ Huron/ Perth (N = 15)	4.53 (.52)	4 – 5
<b>Across all sites (N = 46)</b>	4.33 (1.06)	1 – 5
<b>Third Survey</b>		
Sudbury/ Timmins (N = 1)	5.0	5.0
Kingston (N = 10)	3.70 (1.3)	1 – 5
Ottawa (N = 5)	4.40 (.55)	4 – 5
Grey Bruce/ Huron/ Perth (N = 11)	4.00 (1.0)	2 – 5
<b>Across all sites (N = 27)</b>	4.00 (1.1)	1 – 5

Site	Mean (SD)	Range
<b>Fourth Survey</b>		
Sudbury/ Timmins (N = 0)	N/A	N/A
Kingston (N = 6)	2.83 (2.0)	1 - 5
Ottawa (N = 2)	2.50 (.71)	2 - 3
Grey Bruce/ Huron/ Perth (N = 4)	3.75 (1.5)	2 - 5
<b>Across all sites (N = 12)</b>	3.08 (1.7)	1 - 5
<b>Fifth Survey</b>		
Sudbury/ Timmins (N = 0)	N/A	N/A
Kingston (N = 1)	1.00 (.00)	1
Ottawa (N = 0)	N/A	N/A
Grey Bruce/ Huron/ Perth (N = 0)	N/A	N/A
<b>Across all sites (N = 1)</b>	1.00 (.00)	1

N/A = not applicable (no values)

## BY REFERRAL STATUS

Site	Mean (SD)	Range
<b>Second Survey</b>		
Self-Referred (N = 22)	4.09 (1.3)	1 - 5
Referred via First Link (N = 19)	4.58 (.84)	2 - 5
<b>Total (N = 41)</b>	4.3 (1.1)	1 - 5
<b>Third Survey</b>		
Self-Referred (N = 16)	4.0 (1.2)	1 - 5
Referred via First Link (N = 10)	4.0 (.94)	2 - 5
<b>Total (N = 36)</b>	4.0 (1.1)	1 - 5
<b>Fourth Survey</b>		
Self-Referred (N = 6)	2.5 (2.0)	1 - 5
Referred via First Link (N = 6)	3.67 (1.2)	2 - 5
<b>Total (N = 12)</b>	3.01 (1.7)	1 - 5
<b>Fifth Survey</b>		
Self-Referred (N = 1)	1.0	1
Referred via First Link (N = 0)	n/a	
<b>Total (N = 1)</b>	1.0	

N/A = not applicable (no values)

**Overall, how satisfied are you with the assistance you have received to date from First Link or your local Alzheimer Society Chapter? (5-point scale: 1 = not at all, 5 = extremely satisfied)**

Site	Mean (SD)	Range
<b>Second Survey</b>		
Sudbury/ Timmins (N = 10)	3.90 (1.37)	1 – 5
Kingston (N = 17)	4.06 (1.03)	1 – 5
Ottawa (N = 17)	4.47 (.72)	3 – 5
Grey Bruce/ Huron/ Perth (N = 19 )	4.00 (.75)	3 – 5
<b>Across all sites (N = 92)</b>	4.16 (.94)	1 – 5
<b>Third Survey</b>		
Sudbury/ Timmins (N = 2)	4.50 (.71)	4 – 5
Kingston (N = 13)	3.31 (1.2)	1 – 5
Ottawa (N = 8)	4.13 (.99)	2 – 5
Grey Bruce/ Huron/ Perth (N = 17)	3.65 (.93)	2 – 5
<b>Across all sites (N = 40)</b>	3.68 (1.2)	1 - 5
<b>Fourth Survey</b>		
Sudbury/ Timmins (N = 1)	5.00	5
Kingston (N = 7)	3.57 (1.6)	1 – 5
Ottawa (N = 2)	4.50 (.71)	4 – 5
Grey Bruce/ Huron/ Perth (N = 6)	3.17 (1.2)	1 – 4
<b>Across all sites (N = 16)</b>	3.63 (1.4)	1 – 5
<b>Fifth Survey</b>		
Sudbury/ Timmins (N = 0)	N/A	N/A
Kingston (N = 2)	1.00 (.00)	1
Ottawa (N = 0)	N/A	N/A
Grey Bruce/ Huron/ Perth (N = 0)	N/A	N/A
<b>Across all sites (N = 2)</b>	1.00 (.00)	1

***Paired t-tests - Differences across survey times***

Survey	Mean (SD)	t-test
Survey 2 (Follow-up 1) (N = 39)	4.05 (.89)	t(38) = 2.18, p = .038
Survey 3 (Follow-up 2) (N = 39)	3.72 (1.0)	
Survey 2 (Follow-up 1) (N = 16)	4.00 (1.0)	t(15) = 1.38, p = n.s.
Survey 4 (Follow-up 3) (N = 16)	3.63 (1.4)	

Survey	Mean (SD)	t-test
Survey 3 (Follow-up 2) (N = 16)	3.75 (1.2)	t(15) = .62, p = n.s.
Survey 4 (Follow-up 3) (N = 16)	3.62 (1.4)	

#### BY REFERRAL STATUS

Site	Mean (SD)	Range
<b>Second Survey</b>		
Self-Referred (N = 28)	3.96 (1.1)	1 – 5
Referred via First Link (N = 28)	4.32 (.72)	3 – 5
<b>Third Survey</b>		
Self-Referred (N = 21)	3.62 (1.12)	1 – 5
Referred via First Link (N = 14)	3.79 (.8994)	2 – 5
<b>Fourth Survey</b>		
Self-Referred (N = 8)	2.63 (1.2)	1 – 5
Referred via First Link (N = 7)	4.57 (.53)	4 – 5
<b>Fifth Survey</b>		
Self-Referred (N = 2)	1.0	1
Referred via First Link (N = 0)	n/a	

#### Do you have any comments you would like to make about First Link or you local Alzheimer Society chapter?

**First Survey Additional Comments:** At the end of the caregiver surveys, respondents were invited to share any comments. Many of the additional comments made reflected the struggles and frustrations that caregivers were experiencing related to:

- Getting a diagnosis

*“There seems to a lack of proper diagnosis as the family doctor uses a five item test for the patient to remember and the patient can do quite well yet we as family members see a steady decline. Unfortunately this leads to a lot of frustration for family/ caregivers.”*

*“Because of the doctor shortage in our own area my mother had to wait three months between appointments with the doctor who doesn't even know her. (So he had no benchmarks to judge her memory decline). The next appointment after July 22 I could*

*get was Nov 18. At this rate her decline will outpace her care. This very stressful - more than my mother's behavior."*

*"My care-receiver has probably had the disease for 3 years, but only diagnosed in the last 2 years because no physicians would believe or listen to my daughter or myself."*

- Concern about the future

*"Feeling overwhelmed by the entire situation on most occasions best describes my emotional being. I am also afraid, not knowing what to expect or what will transpire for my mom. I am sad because I have lost my "mom", Yes, I still have my mother but she is no longer the "mom" I knew and counted on. I am glad I can be "there" for my mom now as she needs me and depends on me entirely. I hope I will find ways to keep her in her own home for as long as feasible and safe for her as this is her wish."*

*"My biggest worry is where will this disease take my loved one. i.e., how will she be affected as time goes on? Will it level out and remain the same or will she end up incapacitated."*

*"It is family in denial of his diagnosis which makes it very hard for me to discuss his condition."*

- Conflicts among family members in perceptions of how the care-receiver should be supported.

*"This AD diagnosis comes after 2 years of supporting our mother through a severe depression that necessitated hospitalization. This situation lead to challenges within the siblings ranks, in particular one sibling. For my part, the necessary seemingly constant exposure to this one sibling and her attempts to exert control over how the rest of us should support our mother caused great stress to me."*

*"Of 3 siblings, only one in town. Sister lives in [different city] and wants mom in a retirement home and does not help either by phone call. Brother in [different province] who wants mom to live with his family, but wife disagrees."*

*"It is family in denial of his diagnosis which makes it very hard for me to discuss his condition."*

- Managing psychological and behavioral symptoms

*"Care receiver - good health, doesn't remember to bath, change clothes, etc., accuses me - taking money, trying to put him in nursing home. A struggle to get him to accept help so he can stay in his own place."*

*"It is very dismaying to try to learn to live with the changes that are taking place in my care-receiver (wife). She can be unsettled and combative one minute and sweetness and light the next. As a result one tends to live "on edge" as well as having to be "on guard" for her."*

- Managing care

*"Above stress is related to inefficiency of community care and balancing work/home life, continued fast decline of his ability to function."*

*"My main stress is balancing work and caregiving and worry about the next steps that will likely involve long-term care placement."*

Three respondents commented on the helpfulness of First Link, as reflected in the following comments:

*"...It is 5 months since she was diagnosed as having "moderate cognitive impairment" as a result of observation by our family physician and the Kingston Cognitive Tests. I called Kingston Alzheimer Association 5 weeks ago in desperation and they are helping. Thanks First Link."*

*"...For my part, the necessary seemingly constant exposure to this one sibling and her attempts to exert control over how the rest of us should support our mother caused great stress to me. However, I have worked hard to become stronger myself but must say this diagnosis of Alzheimer's disease is putting my strength to the test in terms of handling family dynamics, again with this one sister. Having the First Link intake worker contact me was like a shot in the arm and I look forward to drawing strength from the program as our situation changes, as it no doubt will as the disease progresses."*

*"I recently attended a First Links seminar which provided excellent information and with other caregivers, enlightened me as to the extent of caregiver needs and solutions to challenges they face."*

*"I have completed 3 of the 5 sessions in First Link. I have 5 other siblings and we are working well to support my mother in her desire to remain at home as long as possible. We have begun to research alternative living arrangements now that my mom is at the moderate stage of Alzheimer's."*

**Second Survey Additional Comments:** At the end of the follow-up surveys, respondents were invited to make additional comments specifically about First Link and their local Alzheimer Society Chapter. The majority of additional comments made in the second survey reflected survey respondents' satisfaction with First Link, in terms of the helpfulness of the information and education sessions, support groups, resources and supports, availability for consultation and



support when needed, and impact on reducing caregiving stress, as reflected in the following comments:

*“The Kingston Alzheimer Society provides a range of excellent services with minimum staff. They have been invaluable in pointing us in the right direction in our quest for help. We have attended several of their programs and would attend more except for scheduling problems at our end as we have Red Cross and VON people coming to the home on certain days. I cannot say enough to thank Kingston Alzheimer Society as being my first point of contact, eight to nine months ago, when I was quite desperate for help. The four sessions conducted by First Link that we attended were well run and most informative. The atmosphere was excellent and the sense that “we were all in this thing together” dealing with problems common to patients and caregivers was very reassuring and in fact humorous at times. Every effort should be made to continue First Link programs as they are just excellent for providing security and hope to individuals and families who are “groping in the dark” to come to grips with the uncertainties as they affect both caregivers and patients at the time Alzheimer’s/dementia has been diagnosed.”*

*“I think my local Alzheimer Society is wonderful. I feel I can contact them with any problem and get help. The support group I attend is very informative and is a source of comfort to me.”*

*“They definitely provide a necessary and excellent support. The respite hours they have given me have really helped decrease my stress level.”*

*“I did attend a daylong seminar for caregivers. It recharged my batteries. The ladies at the Alzheimer Society have been excellent in providing information and support to not only me but my family. They also have been very supportive to my mother helping her realize she has problem and where to get help and support.”*

*“I feel the support is there for me locally, when the needs arises.”*

*“The First Links program has been invaluable to me. The information supplied and the conversation pertaining to that information has helped immensely.”*

*“The Alzheimer Caregiver Support meetings give us a place to vent frustrations and receive suggestions in handling the person.”*

*“Keep up the great work. I find it a comfort to be able to call upon the local Alzheimer Society office in Ottawa. They have been very helpful to me.”*

*“Caregiver series was extremely beneficial. It is so nice to have this level of support available to help navigate new, uncharted territory as the dementia progresses.”*

*“Excellent service- home visit by counselor with follow-up 5 months later. Staff so*

*supportive. Without a doubt my husband and I have been able to cope so much better since attending the program. I am an RN and thought I understood dementia but I found myself lacking vital information, which I only became aware of after attending classes. I am forever grateful for the staff's help and support!"*

Several survey respondents commented that they continue to struggle despite the assistance they have received from First Link, as reflected in the following comments:

*"All the information I have received is informative and mostly helpful. Regrettably, when it comes down to handling difficult incidents at home, not much of the information is helpful because each case/ situation is unique.*

*"The First Link course was very effective and helpful even though my husband and I were still in shock. However, he was the only person attending the course who had dementia related to Parkinson's. The leader seemed to have little information on this. The books on Parkinson's also have little to information. Is the progress the same overtime? How similar/ dissimilar is it to Alzheimer's? Is the medication (he is on Exelor) as effective for dementia for Parkinson's? Is it caused by the disease or the medication he has been taking for 13 years? As you can see I still have many questions."*

Several survey respondents commented on the difficulties they experience attending information/ education sessions/ support groups because they are held at inconvenient times (times inconvenient for those employed during weekday hours) or in inconvenient locations, as reflected in the following comments:

*"I work during the days and consequently am not able to attend the 1 1/2 - 2 hour info sessions that have been scheduled for lunch times. They are too long and too far away from my workplace and I would have to take a half day off to attend. I spoke with the First Link coordinator about this last fall - but so far I've been unable to attend the info sessions held since Oct to date because they're still scheduled during the day."*

*"I would have liked to have stayed with the support group but it was not at a convenient time."*

*"The Alzheimer Society holds meetings during the week (I believe once a month). I have been only to a couple as I work during these times."*

*"There is the occasional day session which is hard to attend as we are both still working."*

Several survey respondents commented on their dissatisfaction with lack of factual information shared at support group meetings, the overwhelming nature of all the information/ sessions provided by the Alzheimer Society, lack of comfort with group format of support groups, the lack of available respite and limited community support services

*“...However, the meetings are only a group of people talking about themselves and their troubles. Little or no information is shared. I get more research from reading and the internet. My family has been trying music therapy as we have read this has a great calming effect and it seems to work most of the time, or old photo albums.”*

*“So much information at one time, not sure how they expect you are going to have time to read it all. Haven't had the time to read. Didn't have time to attend (education sessions). When you have spare time, you don't want to use it attending a meeting. Normal things in life take up those spare hours; groceries, personal care for both people in the family, shoveling snow, cutting grass, cleaning house etc. Not sure if the Alzheimer Society provide anything other than paper related material and workshops. When you do have any spare time you certainly would like something that might be enjoyable, rather than hearing about the problem you are caring for. The Alzheimer Society no doubt provide a wonderful service however in caring for someone I have found the services of [community service provider agency] and some private services more helpful.*

*“I'm involved with local Council on Aging who provide better community resources; as an example holding a meeting without arranging for transportation - I don't drive and my husband's license was suspended. Because my sister-in-law had Alzheimer's, we are very aware of the progress of the disease. The sessions were led by a young social worker and the question was always asked" "What problem are you having?" Most seniors do not want to share in a group - we were raised to "not wash your dirty linen in public." A better approach in my view would be to establish a peer support - one- on-one with an experienced, trained senior. Isolation is the other issue we are facing and a social event planning group would be most welcome! I apologize for the lateness in responding - because I didn't want to be negative - knowing the local society is trying to help!”*

*“Need more than one day way per week or some other respite care option.”*

*“[Community provider agency] does not show up half of the time they cancel often and are unable to replace with anyone else. Overall I'm not getting the help I need and it's getting worse.”*

Suggestions for improvement included the development of a program (education and support) for those with early diagnosis, a strategy for overcoming the stigma associated with ADRD, programs targeting lower income clients, and a clear differentiation of all of the Alzheimer Society programs (“branding”) as described in the following comments:

*“I think it would be useful for a program for early diagnosis patients to attend, to gain information on how this disease will affect them. Knowledge = power = ability to accept, prepare and combat. For some patients this would be a welcome program. In addition, the need for a forum to vent and exchange feelings and ideas is important as not everyone likes to be kept in the dark re the changes that are happening to them.”*

*“No program to overcome the general public's stigma relative to dementia/ Alzheimer. 2. Need program to encourage lower income people to avail themselves of the services of the Alzheimer Society. 3. Need to "brand" more clearly each of the AS's programs (clearly differentiate one from the other). I would be delighted to discuss further.”*

### **Third and Fourth Survey Additional Comments:**

Similar to the additional comments made in the second survey, many survey respondents commented on their satisfaction with First Link, in terms of the education and support provided, regular contact from First Link, helpfulness of the information and education sessions, support groups, resources and supports, availability for consultation and support when needed, and impact on ability to cope, as reflected in the following comments:

*“We regularly attend the sessions twice a month at the local Alzheimer Society. The social workers are extremely knowledgeable and sympathetic. My spouse looks forward to the meetings. It's a great support group that helps one feel they are not alone in this journey.”*

*“I attended one [education session] earlier that was most helpful. I am contacted each month and reminded of support group meetings. We have wonderfully caring people in our chapter.*

*“These people make a big difference. I couldn't survive without them. They are very important to the care-receiver, more than the medical personnel.”*

*“We belong to an Alzheimer's group in Belleville. They are very helpful. I have learned a lot from going to these meetings. I have registered [care receiver] with Safely Home.”*

*“I have always found those First Link meetings very helpful - not just with the provided information or program but a lot from the other attendees - the discussing and sharing of each others situation has been very helpful.”*

*“We belong to the local Circle of Friends and find the meetings very good. After 9 years we are still looking after ourselves.”*

Several survey respondents commented that their care receivers' denial of their diagnosis prevents them participating in more fully in programs available through First Link:

*“I am unable to fully participate in programs offered by the Alzheimer Society because my husband refuses to acknowledge he has Alzheimer's so refuses to attend any programs.”*

*“Many things cannot be addressed with the person affected, as she denies she has a problem and generally refuses offers of help - very frustrating.”*

*“Will be more value to us when the care receiver reaches a much lower level of cognition. The person involved still refuses to believe she has the disease at present.”*

*“...I would love to continue going to the support circles, but my mother refuses to go...”*

Several survey respondents commented on their dissatisfaction with First Link/ Alzheimer Society, related to receiving too many calls for charitable donations, perceptions of patronizing attitude of information sessions, need for confidentiality, one-on-one counseling sessions, and practical information about community resources, and limited access to respite, as described in the following comments:

*“I haven’t received any help from the Society because I haven’t requested any. I am coping well as can be expected and my husband is rather easy to care for. I have received too many requests for money from the Society.”*

*“As a seniors’ advocate I was knowledgeable prior to diagnosis of my husband with Alzheimer which is now under question. Re: Information Sessions - Patronizing attitude had me in tears and feeling sorry for myself. Comments such as “We want to share your burden.” “Let’s share our problems” In a group of people where there was no mention of confidentiality and this city is a small city. Counseling should be on a one to one basis. Practical help such as who delivers groceries etc is missing from this program! My spouse was equally disturbed by kindergarten games used the group of recently diagnosed adults. Going to the theatre etc would help those who are now isolated!”*

*“Very paternalistic - not down to earth. Pat’s on the shoulder - “poor you” attitude and “how awful!”*

*“Day away is actually only 1/2 day away and doesn’t help much. Picked up at 9:30am is too late in the morning and being returned 3:15 is too early in the afternoon. Need full day program for the cost (8am-830am to 430-500pm) even if I could drop off and pick up but they said no.”*

Suggestions for improvements included the development of information/ support programs targeting persons with dementia, more formal education sessions for caregivers, support groups targeting older seniors with affected spouses (rather than support groups for younger aged children of persons with dementia, holding evening education sessions, regular contact from First Link after initial for those who may not attend support services,

*“Most information is directed to the caregiver. It would be very helpful for literature and group support sessions directed towards the affected individual. This disease affects and changes their life - they need to be able to learn, vent, understand what is happening to them. Most don’t have computer skills/ access and therefore need paper copy and personal contact. 2. Retirement and long-term care facilities should offer once or twice monthly info and/or support sessions for clients and/ or caregivers.”*

*“Again, I would like to see more information sessions/ seminars to educate caregivers. The informal meetings are get together for coffee and stories.”*

*“Support group for my senior age group with a spouse with dementia is not available. Groups are mixed with mostly younger attendees having parents with onset Alzheimer’s. After nearly 2 y ears of attending support groups, I no longer go. Individual counseling still available on request and is very helpful when accessed.”*

*“The information given by the local chapter included information about a series of talks related to caring for/dealing with Alzheimer sufferers. I would have liked to attend these talks; however, they have always been scheduled for 1 1/2 - 2 hours periods during the day. It is very difficult for me to leave my workplace for that length of time (plus travel time) and impossible for me to do so on a regular basis. I asked the First Link Coordinator here about having evening lectures - she was encouraging, but so far I've seen no sign that this is happening.”*

*“Wish there was more contact with First Link. There is support there but you must go to it. I wish there was more random support from the Alzheimer Society. As to First Link, after the initial contact, there does not seem to be any further contact except for these surveys.”*

**Fourth surveys:** no comments

## APPENDIX R: Results of the Health Professional Survey

N = 63

### With which First Link site are associated?

17.5% (11)	Sudbury/ Timmins
23.8% (15)	Kingston
36.5% (23)	Ottawa
12.7% (8)	Grey Bruce/ Huron/ Perth

Differences among sites:  $\chi^2(3) = 8.9, p < .05$ .<sup>17</sup>

Note: Percentages do not sum to 100% due to missing values (N = 6; 9.5% did not identify their site)

**We are interested in learning more about your involvement with the Alzheimer Society's First Link program and how helpful this has been to you.**

**In the past year have you received any written material about Alzheimer disease and related dementias from First Link or your local Alzheimer Society chapter?**

	Ottawa (N = 23)	Kingston (N = 15)	Grey Bruce/ Huron/ Perth (N = 8)	Sudbury/ Timmins (N = 11)	Site Unknown (N = 6)	Total (N = 63)
No	8.7% (2)	13.3% (2)	12.5% (1)	9.1% (1)	33.3% (2)	12.7% (8)
I don't recall	13.0% (3)	13.3% (2)	0	9.1% (1)	16.7% (1)	11.1% (7)
Yes	78.3% (18)	73.3% (11)	87.5% (7)	81.8% (9)	50.0% (3)	76.2% (48)

Note: Percentages may not sum to 100% due to missing responses.

**If yes, how helpful was this information to you? (5-point rating scale: 1 = not at all helpful; 5 = extremely helpful)**

	Ottawa (N = 17)	Kingston (N = 11)	Grey Bruce/ Huron/ Perth (N = 7)	Sudbury/ Timmins (N = 9)	Site Unknown (N = 4)	Total (N = 48)
Mean (SD)	3.94 (.56)	4.09 (.70)	4.29 (.95)	4.44 (.73)	3.50 (.58)	4.08 (.71)
Range	3 - 5	3 - 5	3 - 5	3 - 5	3 - 4	3 - 5

<sup>17</sup> Where significant, differences between sites are reported.



**In the past year have you received any information about community resources or services that are available to your patients with dementia from First Link or your local Alzheimer Society Chapter?**

	<b>Ottawa (N = 23)</b>	<b>Kingston (N = 15)</b>	<b>Grey Bruce/ Huron/ Perth (N = 8)</b>	<b>Sudbury/ Timmins (N = 11)</b>	<b>Site Unknown (N = 6)</b>	<b>Total (N = 63)</b>
No	13.0% (3)	6.7% (1)	% (0)	18.2% (2)	50.0% (3)	14.3% (9)
I don't recall	26.1% (6)	27.3% (2)	12.5% (1)	27.3% (3)	16.7% (1)	20.6% (13)
Yes	60.9% (14)	54.5% (12)	87.5% (7)	54.5% (6)	33.3% (2)	65.1% (41)

Note: Percentages may not sum to 100% due to missing responses.

If yes, how helpful was this information to you? (5-point rating scale: 1 = not at all helpful; 5 = extremely helpful)

	<b>Ottawa (N = 14)</b>	<b>Kingston (N = 12)</b>	<b>Grey Bruce/ Huron/ Perth (N = 7)</b>	<b>Sudbury/ Timmins (N = 6)</b>	<b>Site Unknown (N = 2)</b>	<b>Total (N = 41)</b>
Mean (SD)	4.21 (.43)	4.25 (1.1)	4.57 (.53)	4.50 (.84)	4.00 (.00)	4.32 (.76)
Range	4 - 5	1 - 5	4 - 5	3 - 5	4	1 - 5

**Please identify one or two things that you learned about Alzheimer Disease and related dementias (e.g., related to assessment, diagnosis, best practices, available community resources) as a result of your involvement with First Link or your local Alzheimer Society Chapter that you have found particularly useful.**

- *Not applicable - specialize in psycho-geriatric assessment*
- *I learn that the clients I see are grateful for the support they receive from the Alzheimer Society and First Link program to help them manage their care giver roles and improve their understanding of the disease process.*
- *-staff are very helpful in their communications with family, great resource in the community -copies of the in home cognitive assessment that the staff complete.*
- *Particulars related to clients assessed*
- *Increased awareness of community resources in this county*
- *Information about different assessments that can be completed medications*
- *Nothing, but only because I diagnose dementia very frequently as a result of my practice, so I'm "supposed" to be an expert.*
- *Lack of community resources Supportive counseling from First Link*
- *New treatments hand out info for client's relatives*
- *Reminded to refer to service more comprehensive than realized*
- *Groups available through Alzheimer Society for support/ education to clients in early stage dementia and caregivers.*



- Availability of group appropriate for client/ families at different stages of the Alzheimer Journey. Information about challenging behaviours.
- New agency provided trained PSWs Educational opportunities New support group
- Upcoming community education days
- Communication Techniques
- More prevalent if client suffering from diabetes, cardiac
- Caregiver education sessions.
- Community resources
- Local resources Support groups for families
- Practical info regarding management of behavioral issues in dementia
- Increased info re: availability of "day away programs" Resources for caregivers - education, group support sessions.
- The availability to have educational sessions for family and support for the person
- That there are various types of dementias. That there are some drugs out there that can help in the early stages. That there are services such as First Link to connect the family/individual to help. That the Alzheimer Society offers supportive and educational programs
- First Link has been very helpful in assisting patients/families who are reluctant, or have difficulty, in making that first contact to the immense resources and support available through the Alzheimer Society. It is a tremendous resource.
- Commitment of First Link to help caregivers
- Access to care services Programs for caregivers and for stress education
- Community resources for family support
- Community resources
- Don't recall
- Community resources for patients Guest house program
- Have taught the GPA with our PEC. Have completed joint visits with mutual clients. PEC is involved with Pieces group. First link person has attended my geriatric medicine outreach as well. We have a good working relationship. I attend all the educational opportunities provided by the Alzheimer Society. To outline more here would be extensive.
- First Link has relocated at the Golden Manor and this makes the Alzheimer Society far more accessible to the families of residents in the Long Term Facility
- Caregiver support services
- Have been given a resource package (to give to pts/families) when diagnosis with dementia filled with lots of good resources!! Also like the "heads up for healthier living" pamphlet and give it out +++ always refer to First Link with diagnosis of AD - like to referral forms
- I think the most helpful is being able to explain the difference between A.D., Vascular, Mixed etc. This often reassures the families I work with.
- Not sure how I should answer this one since I Managed the Program.

- Differences in types of dementias. Tips to give to caregivers. The available programs and accommodation options for people with dementia
- I'm part of a assessment team .first link is good referral source for the family and the patient .the received good support there
- I am already quite aware about the disease and the community resources available. The First Link has been a great resource for my clients...I have made numerous referrals to the First Link program.
  - Information on the various education programs for patients & family - Information on services First Link offers to patients and families
- Timmins Family Health Geriatric nurse joins with Alzheimer society to provide caregiver support classes Patient education material Website very useful for patients and health care providers
- As a specialist in dementia diagnosis I found I was still able to learn from first Link and the Alzheimer society. Specifically I was able to learn about care issues and community resources.
- I have been involved with First link in Ottawa since its inception. It is extremely helpful to my patients to 1. Link them with community resources and education when they are first diagnosed 2. Provide the opportunity for further education and information as they go thru their Alzheimer's journey, and hit key points, e.g. need for placement.
- How to distinguish from normal forgetfulness 2. Difference between Alzheimer's and Vascular dementia
- -information on support groups and information sessions (i.e. First Steps) for families and patients -information on caregiver stress
- Availability of specific supports for patients and caregivers
- Nothing 'new'. We have not received any reports back from First Link of the clients we have referred. I admit we have been slow at starting the referral process but with better awareness this should improve.
- I have found the information about education sessions, availability of the family support worker, web site info very useful and I frequently communicate this to families. The working relationship with the First Link Coordinator has enhanced the feeling of being able to offer family something tangible to support them.

## PRACTICE RELATED TO DEMENTIA CARE

**To what extent has First Link had an impact on increasing the number of patients diagnosed with Alzheimer Disease and related dementias in your practice / organization? (5-point rating scale: 1 = not at all; 5 = a great deal)**

	Ottawa (N = 20)	Kingston (N = 14)	Grey Bruce/ Huron/ Perth (N = 8)	Sudbury/ Timmins (N = 10)	Site Unknown (N = 1)	Total (N = 53)
	2.10 (1.3)	2.00 (1.2)	2.75 (1.0)	3.10 (1.5)	1.00 (.)	2.34 (1.3)

Mean (SD)						
Range	1 - 5	1 - 4	1 - 4	1 - 5	1	1 - 5

**Do you have any comments that you would like to make about this?**

- *I refer to First Link from the client base that I see for support as part of my employment.*
- *It has been helpful when referring clients, great pt. of access, great when f/u.*
- *I work in a specialized setting where patients are referred because of memory complaints, so I already diagnosed a lot of dementia.*
- *It hasn't changed how many I diagnose - it has changed how many end up with contact with the Alzheimer Society.*
- *Not many referred from Alzheimer Society*
- *I am a social worker/ assessor, Outreach Specialized Geriatrics - we discern dementia, our physicians would diagnose, or patients/ clients come to our service with a diagnosis.*
- *Not sure as don't recall if info received on dementia was from First Link*
- *First Link is a service discussed after diagnosed.*
- *My team diagnosing dementias and then we refer to First Link - initiate the service*
- *In Ottawa the diagnosis is done by Elizabeth Bruyere Hospital and the Memory Disorder clinic. First Link is where I send my families once diagnosis is done. Like sending them to school to learn how the rest of their life will unfold.*
- *Those who are referred to use from First Link/ or Alzheimer Society have been diagnosed.*
- *I receive patients on referral from family practitioners.*
- *Course I took about 5 years had greatest impact on increased frequency of diagnosis (mainproC)*
- *We are a day program at a psychiatric hospital so people are here to get testing, screening for dementia - reason for the referrals here.*
- *I don't know that First Link increases the number of patients I diagnose. The people I see using First Link are family members/ caregivers, struggling with the diagnosis.*
- *I am not sure how many of your practitioners have used the service. I know we have a support group that meets monthly at the centre so they are well informed but I'm not sure about the newly diagnosed as I tend to work with the support groups and education programs*
- *Many people are not comfortable with their family physician or are not feeling 'heard' by their family physician. Building that connection with the Alzheimer Society helps people learn about, plan for and adjust to dementia. They are feeling 'heard' and less frustrated.*
- *Not relevant - I felt very comfortable with AD diagnosis without First Link impact given my professional training & experience*
- *I do not know that it has an impact on increasing the number of patients diagnosed with dementia, but it has increased the number of referrals coming to the Day Program.*
- *I think it is good that we are diagnosing patients earlier.*

- *I keep up-to-date by reading the "Canadian Journal of Alzheimer's Disease and Other Dementias" and a "Dementia Newsletter" sent by a group of local geriatricians in Ottawa. I do not use First Link for educational purposes.*
- *I already screen for dementia, do MMSE, MOCA etc., so I diagnose early. This program for me does not add to diagnosis but helps with patients and their families.*
- *Provide useful updates and info*
- *First link program has been presented to our providers however we need to be reminded sometimes. The Physician group is a challenge.*
- *There may be an impact that I am not aware of as I do not have direct contact with families on admission and only occasionally once residents have been admitted as it pertains to staff performance.*
- *I am unable to specifically state the extent to which this statement may or any not be true but I believe there is an impact arising from general community awareness.*
- *I refer patients who are already diagnosed with dementia to First link for more information*
- *likely advertising in the community drives people into clinic for assessments - this would be more difficult to determine - I have had people in lately for assessments that are more aware of dementia b/c of the increased media last month*
- *I am not sure. Our Geriatrician makes the diagnosis, but we then refer on to First Link for the purpose of supporting and educating our client's. So, I think the number of referrals to First Link have increased because of our referrals to your wonderful service.*
- *Without FL many client were fallen between the cracks without services and now they not only receiving education and support through the AS but also other service providers.*
- *Our clinic still has undiagnosed patients. Inappropriate screening and risk assessment for the moment.*
- *Because information about ad and related dementias are more accessible. Health professional and family members are more informed about signs and symptoms .more people are referred for treatment or assessment.*
- *I work with the Geriatric Assessment Outreach Team which receives the majority of referrals from GPs/clients/family members/CCAC to assess cognition. I know that the Alz Soc. encourages families/clients to be assessed through us but I don't recall a direct referral so can't comment on the increase in referrals due to the Alz Soc.*
- *We send our referral to the Alzheimer society, they contact the caregiver and provide support to the patient and family thru their diagnosis*
- *I am a dementia neurologist, all my patients have cognitive disorders.*
- *The doctors make the diagnoses of dementia.*
- *I work in the Geriatric Day Hospital so we have continued to diagnose at the same rate regardless of First Link but really appreciate the follow-up and support.*
- *Again partly related to our lack of use of First Link services which is partly due to lack if provided info and initial prompting from First Link.*

- *I am not sure about this. We have had some referrals from family members who told us that First Link suggested they call. We receive the majority of our referrals from GP's who do not tell us how they heard about our agency.*

**How familiar are you with services and supports provided by the Alzheimer Society (e.g., First Link, support groups, information sessions) in your community? (5-point rating scale: 1 = not at all familiar; 5 = extremely familiar)**

	Ottawa (N = 22)	Kingston (N = 15)	Grey Bruce/ Huron/ Perth (N = 8)	Sudbury/ Timmins (N = 11)	Site Unknown (N = 1)	Total (N = 57)
Mean (SD)	3.86 (.89)	4.13 (.99)	3.75 (1.2)	4.09 (.83)	4.00 (.)	3.96 (.93)
Range	2 – 5	2 - 5	1 – 4	3 - 5	4	1 - 5

**How often do you refer patients to First Link and/or the Alzheimer Society?**

	Ottawa (N = 23)	Kingston (N = 15)	Grey Bruce/ Huron/ Perth (N = 8)	Sudbury/ Timmins (N = 11)	Site Unknown (N = 6)	Total (N = 63)
N/A*	0	0	25.0% (2)	18.2% (2)	16.7% (1)	7.9% (5)
With none or hardly any of my patients	0	6.7% (1)	0	0	0	1.6% (1)
With a few of my patients	17.4% (4)	20.0% (3)	0	9.1% (1)	0	12.7% (8)
With most of my patients	52.2% (12)	66.7% (10)	62.5% (5)	63.6% (7)	0	22.2% (14)
With all of my patients	30.4% (7)	6.7% (1)	0	9.1% (1)	0	14.3% (9)

Note: Percentages may not sum to 100% due to missing responses.

\* Not applicable (It is not my role to refer patients to these types of services)

**Do you think that the number of patients you refer to the Alzheimer Society has changed as a result of First Link?**

5-point scale	Ottawa (N = 23)	Kingston (N = 15)	Grey Bruce/ Huron/ Perth (N = 8)	Sudbury/ Timmins (N = 11)	Site Unknown (N = 6)	Total (N = 63)
1 Now referring less	0	0	0	0	0	0
2	0	0	12.5% (1)	0	0	1.6% (1)
3 Referring the same	21.7% (5)	33.3% (5)	37.5% (3)	27.3% (3)	0	25.4% (16)

4	26.1% (6)	0	12.5% (1)	18.2% (2)	0	14.3% (9)
5 Now referring more	52.2% (12)	66.7% (10)	25.0% (2)	45.5% (5)	16.7% (1)	47.6% (30)

Note: Percentages may not sum to 100% due to missing responses.

**How familiar are you with the community support services (e.g., respite care, home help, home safety systems) for Alzheimer Disease and related dementias that are available in your community? (5-point rating scale: 1 = not at all familiar; 5 = extremely familiar)**

	Ottawa (N = 23)	Kingston (N = 15)	Grey Bruce/ Huron/ Perth (N = 8)	Sudbury/ Timmins (N = 11)	Site Unknown (N = 1)	Total (N = 58)
Mean (SD)	3.96 (1.0)	4.40 (.83)	4.13 (1.1)	4.36 (.67)	5.00 (.)	4.19 (.93)
Range	1 - 5	3 - 5	2 - 4	3 - 5	5	1 - 5

**How often do you refer patients for these community support services?**

	Ottawa (N = 23)	Kingston (N = 15)	Grey Bruce/ Huron/ Perth (N = 8)	Sudbury/ Timmins (N = 11)	Site Unknown (N = 6)	Total (N = 63)
N/A *	4.3% (1)	0	12.5% (1)	9.1% (1)	0	4.8% (3)
With none or hardly any of my patients	0	0	0	0	0	0
With a few of my patients	17.4% (4)	33.3% (5)	12.5% (1)	0		15.9% (10)
With most of my patients	39.1% (9)	53.3% (8)	37.5% (3)	72.7% (8)	16.7% (1)	46.0% (29)
With all of my patients	34.8% (8)	13.3% (2)	25.0% (2)	18.2% (2)	0	22.2% (14)

Note: Percentages may not sum to 100% due to missing responses.

\* Not applicable (It is not my role to refer patients to these types of services)

**Do you think that the number of patients you refer to community support services has changed as a result of First Link?**

	Ottawa (N = 23)	Kingston (N = 15)	Grey Bruce/ Huron/ Perth (N = 8)	Sudbury/ Timmins (N = 11)	Site Unknown (N = 6)	Total (N = 63)
1 Now referring less	0	0	0	0	0	0
2	4.3% (1)	6.7% (1)	0	0	0	3.2% (2)



3 Referring the same	65.2% (15)	53.3% (8)	50.0% (4)	63.6% (7)	16.7% (1)	55.5% (35)
4	8.7% (2)	26.7% (4)	37.5% (3)	18.2% (2)	0	17.4% (11)
5 Now referring more	21.7% (5)	6.7% (1)	0	18.2% (2)	0	15.1% (8)

Note: Percentages may not sum to 100% due to missing responses.

## IMPACT OF FIRST LINK

**We would like to learn more about whether First Link has heightened health professionals' awareness of Alzheimer disease and related dementias.**

**To what extent do you think that First Link has an impact on your ability to identify or recognize dementia sooner/earlier than you did before? (5-point rating scale: 1 = not at all; 5 = very much so)**

	Ottawa (N = 22)	Kingston (N = 14)	Grey Bruce/ Huron/ Perth (N = 8)	Sudbury/ Timmins (N = 11)	Site Unknown (N = 1)	Total (N = 56)
Mean (SD)	2.41 (1.2)	1.79 (.89)	2.88 (.84)	3.00 (1.3)	1.00 (.)	2.41(1.2)
Range	1 – 4	1 – 3	2 – 4	1 - 5	1	1 - 5

**Differences between sites:**  $F(3, 51) = 2.9, p < .05$ ; Post Hoc tests (Tukey HSD) confirm significant differences in means between Sudbury ( $M = 3.0$ ) and Kingston ( $M = 1.8$ ) and between Kingston (1.8) and Grey Bruce (2.9).

**Do you have any comments that you would like to make about this?**

- I now refer even with the slightest memory/cognitive issues, whether or not related to Alzheimer's. I leave it to the assessor to determine and make recommendations. I am more comfortable doing so because of the response I get from First Link.*
- I believe that more families have had contact/ support of the Alzheimer Society due to the fact that First Link reaches out and initiates the contact with client/ family.*
- Again - I am a geriatrician!*
- Not sure*
- Diagnose as usual- then refer to First Link*
- The focus has been teaching families how to navigate the system and their disease. I have not felt that they were there for teaching the professional.*
- First Link has been very beneficial for families/ patients to accept the diagnosis.*
- I do long-term care and have a lot of geriatric practice.*
- I only see patients with cognitive deficits and/or mood disorders on referral.*

- *I get a newsletter - I believe from the Alzheimer Society. It contains very practical information re; diagnosis, management (often written by local health professionals).*
- *I have had many other presentations from the Alzheimer Society here at the Health Centre before First Link came along so from a personal and community education perspective it has not made a big difference. However I has First Link staff speak at a staff meeting and forms were handed out so hopefully the overall staff were better educated as a result of the presentation*
- *I have much experience and clinical training in this area.*
- *I already screen for dementia, do MMSE, MOCA etc., so I diagnose early. This program, for me does not add to diagnosis but helps with patients and their families.*
- *Good educational resources*
- *I have been working with Seniors and their families in various setting for almost 25 yrs, and I would say that recognizing the signs and symptoms earlier as been gradual with experience as well as through the education/awareness raising by the Alzheimer Society.*
- *I think they are doing a wonderful job, and family physicians are referring more, as the awareness is heightened*
- *I have worked with dementia for a long time - geriatric NP - First Link was already established in this community when I came to practice therefore don't have a clear "before and after" picture did not have First Link in the last community I worked in however had a very strong relationship with the Alzheimer Society there*
- *As information is disseminated in the community I certainly read and review what comes out. It does help me to recognize different symptoms, characteristics etc.*
- *The impact is on other health professional who are not working in the field.*
- *Diagnosis of dementia is my area of clinical expertise so it was unlikely for a program to enhance this area. This question is more relevant to generalist clinicians*
- *I am a dementia neurologist-- our clinic specializes in early detection.*
- *I am a Social Worker and work with Geriatricians who do the diagnosing/identifying, etc of dementia, so this was never my role, but with more education, I can assist families earlier.*
- *Number of patients is directly related to the physician in charge of the patient. Not all physicians see the purpose, gain to be had from this referral.*
- *Being a referral center for dementia First Link has not increase my awareness of the disease but has help tremendously in the management of patients.*
- *Really too soon to make this type of evaluation. We will have to wait and see what reports tell us after First Link involvement.*
- *I work in an agency which is involved in recognizing dementia and referring for assessment, so I was quite aware already, but I believe I use the Alzheimer Society web site more often now that First Link is top of mind.*



**How would you rate your current level of understanding of dementia as a result of First Link?**

<i>Level of understanding about...</i>	<b>Site</b>	<b>1 Understand less</b>	<b>2</b>	<b>3 The same</b>	<b>4</b>	<b>5 Understand more</b>
Dementia in general	Timmins/Sudbury	0	0	45.5% (5)	18.2% (2)	27.3% (3)
	Ottawa	0	0	47.8% (11)	43.5% (10)	8.7% (2)
	Grey Bruce/Huron/ Perth	0	0	62.5% (5)	37.5% (3)	0
	Kingston	0	0	66.7% (12)	13.3% (2)	0
	Site Unknown	0	0	16.7% (1)	0	0
	<b>Total (N = 63)</b>	0	0	54.0% (34)	27.0% (17)	7.9% (5)
Identifying seniors with dementia	Timmins/Sudbury	0	0	54.5% (6)	18.2% (2)	18.2% (2)
	Ottawa	0	0	65.2% (15)	26.1% (6)	8.7% (2)
	Grey Bruce/Huron/ Perth	0	0	50.0% (4)	50.0% (4)	0
	Kingston	0	0	86.7% (13)	6.7% (1)	% (0)
	Site Unknown	0	0	16.7% (1)	0	0
	<b>Total (N=63)</b>	0	0	61.9% (39)	20.6% (13)	6.3% (4)
Managing seniors with dementia	Timmins/Sudbury	0	0	54.5% (6)	27.3% (3)	9.1% (1)
	Ottawa	0	0	39.1% (9)	26.1% (6)	30.4% (7)
	Grey Bruce/Huron/ Perth	0	0	37.5% (3)	62.5% (5)	0
	Kingston	0	0	77.7% (10)	6.7% (1)	20.0% (3)
	Site Unknown	0	0	16.7% (1)	0	0
	<b>Total (N=63)</b>	0	0	46.0% (29)	39.7% (25)	17.5% (11)

Note: Percentages do not sum to 100% due to missing values

**How would you rate your current level of understanding of the supports and services available to those with dementia as a result of First Link?**

<i>Level of understanding about...</i>	<b>Site</b>	<b>1 Understand less</b>	<b>2</b>	<b>3 The same</b>	<b>4</b>	<b>5 Understand more</b>
Role of the Alzheimer Society	Timmins/Sudbury	0	0	27.3% (3)	36.4% (4)	36.4% (4)
	Ottawa	0	0	26.1% (6)	43.5% (10)	26.1% (6)
	Grey Bruce/Huron/ Perth	0	0	37.5% (3)	62.5% (5)	0
	Kingston	0	0	33.3% (5)	33.3% (5)	26.7% (4)
	Site Unknown	0	0	16.7% (1)	0	0
	<b>Total (N=63)</b>	0	0	28.6% (18)	38.1% (24)	22.2% (14)
Available community resources	Timmins/Sudbury	0	0	36.4% (4)	36.4% (4)	27.3% (3)
	Ottawa	0	0	30.4% (7)	43.5% (10)	21.7% (5)
	Grey Bruce / Huron/ Perth	0	0	62.5% (5)	37.5% (3)	0
	Kingston	0	0	40.0% (6)	33.3% (5)	20.0% (3)
	Site Unknown	0	0	16.7% (1)	0	0
	<b>Total</b>	0	0	36.5% (23)	34.9% (22)	17.5% (11)

Note: Percentages do not sum to 100% due to missing values

**Overall, how satisfied are you with the services provided by First Link? (5-point rating scale: 1 = not at all satisfied; 5 = extremely satisfied)**

	<b>Ottawa (N = 23)</b>	<b>Kingston (N = 14)</b>	<b>Grey Bruce/ Huron/ Perth (N = 8)</b>	<b>Sudbury/ Timmins (N = 11)</b>	<b>Site Unknown (N = 1)</b>	<b>Total (N = 57)</b>
Mean (SD)	4.74 (.45)	4.36 (1.2)	4.25 (.71)	4.45 (.69)	4.00 (.)	4.51 (.76)
Range	4 – 5	1 – 5	3 – 5	3 - 5	4	1 - 5

## DEMOGRAPHIC INFORMATION

**What is your discipline?**

<b>Discipline</b>	<b>Ottawa (N = 23)</b>	<b>Kingston (N = 15)</b>	<b>Grey Bruce/ Huron/ Perth (N = 8)</b>	<b>Sudbury/ Timmins (N = 11)</b>	<b>Site Unknown (N = 6)</b>	<b>Total (N = 63)</b>
Family Physician/	21.7 % (5)	40.0% (6)	25.0% (2)	0	0	20.6% (13)

<b>Discipline</b>	<b>Ottawa (N = 23)</b>	<b>Kingston (N = 15)</b>	<b>Grey Bruce/ Huron/ Perth (N = 8)</b>	<b>Sudbury/ Timmins (N = 11)</b>	<b>Site Unknown (N = 6)</b>	<b>Total (N = 63)</b>
General Practitioner						
Specialist: neurologist, geriatrician, geriatric psychiatrist	13.0% (3)	13.3% (2)	0	9.1% (1)	0	9.5% (6)
Allied health professional: Registered Nurse, Nurse Practitioner, Mental Health Counsellor, Social Worker	60.9% (14)	46.7% (7)	62.5% (5)	63.6% (7)	0	46.0% (29)
Other, please specify:	<ul style="list-style-type: none"> <li>• 8.9% (2)</li> <li>• <i>Family Physician with Care of the Elderly Training</i></li> <li>• <i>Neuro-psychologist</i></li> </ul>	0	12.5% (1) <ul style="list-style-type: none"> <li>• <i>Health Promoter</i></li> </ul>	27.3% (3) <ul style="list-style-type: none"> <li>• <i>Director of Nursing</i></li> <li>• <i>Geriatric Resource Education Coordinator</i></li> <li>• <i>Supervisor of Home Support Programs</i></li> </ul>	0	9.5% (6)

Note: Percentages do not sum to 100% due to missing values.

**Where do you work? Please select the one response choice that best describes where you practice.**

<b>Discipline</b>	<b>Ottawa (N = 23)</b>	<b>Kingston (N = 15)</b>	<b>Grey Bruce/ Huron/ Perth (N = 8)</b>	<b>Sudbury/ Timmins (N = 11)</b>	<b>Site Unknown (N = 6)</b>	<b>Total (N = 63)</b>
Family Health Team (FHT)	13.0 % (3)	20.0% (3)	37.5% (3)	18.2% (2)	0	17.5% (11)
Community Health Centre (CHC)	0	0	12.5% (1)	0	0	1.6% (1)
Primary health care in settings other than FHTs and CHCs	17.4% (4)	20.0% (3)	12.5% (1)	9.1% (1)	0	14.3% (9)
Community Care Access Centre	4.3% (1)	0	25.0% (2)	36.4% (4)	0	11.1% (7)
Specialized Clinics / Care Teams (e.g., geriatric medicine, geriatric psychiatry)	60.9% (14)	53.3% (8)	12.5% (1)	18.2% (2)	0	39.7% (25)
Other, please specify	4.3% (1) <i>Acute Care (Psychiatry)</i>	6.7% (1) <i>Acute Care (Emergency)</i>	0	18.2% (2) <i>Long-term care home</i>	0	6.3% (4)

**What percentage of the individuals in your practice/organization would you estimate are over 65 years of age?**

	Ottawa (N = 17)	Kingston (N = 11)	Grey Bruce/ Huron/ Perth (N = 7)	Sudbury/ Timmins (N = 7)	Site Unknown (N = 0)	Total (N = 42)
Mean (SD)	64.4 (38.6)	67.4 (34.6)	50.9 (36.6)	4.45 (.69)	n/a	65.8 (35.1)
Range	5– 100%	18 – 100%	6 – 95%	3 – 5%	n/a	5 - 100

**Percentage of the individuals over 65 years of age by practice setting**

Practice setting	Mean (SD)	Range	Number
Primary Care	33.89 (26.0)	5 – 90%	19
Specialized Clinics	95.10 (11.1)	60-100%	17
CCAC	83.00 (10.4)	70 – 95%	5

**Differences by practice setting** (ANOVA): Health Professionals working in Specialized Clinics and the CCAC have a significantly higher percentage of individuals in their practice that are over 65 years of age (M = 95.10, SD = 11.1; M = 83.00, SD = 10.4, respectively) than those working in Primary Care settings (FHTs, CHCs, other primary care settings; M = 33.89, SD = 26.0),  $F(1.38) = 46.01$ ,  $p < .001$ .

**What percentage of the individuals in your practice/organization would you estimate have Alzheimer Disease or a related dementia?**

	Ottawa (N = 16)	Kingston (N = 12)	Grey Bruce/ Huron/ Perth (N = 8)	Sudbury/ Timmins (N = 6)	Site Unknown (N = 0)	Total (N = 42)
Mean (SD)	41.9 (39.1)	37.6 (38.5)	4.25 (.71)	66.7 (25.4)	n/a	42.3 (37.3)
Range	0 – 95%	3 – 99%	1 – 90%	35-100%	n/a	0 -100

**Percentage of the individuals with ADRD by practice setting**

Practice setting	Mean (SD)	Range	Number
Primary Care	15.72 (26.3)	1 - 85%	18
Specialized Clinics	67.17 (28.4)	0 - 99%	18
CCAC	37.00 (32.9)	5 - 90%	5

**Differences by practice setting** (ANOVA): Health Professionals working in Specialized Clinics have a significantly higher percentage of individuals in their practice that have ADRD (M = 67.17, SD = 28.4) than those working in Primary Care settings (FHTs, CHCs, other primary care settings) and the CCAC (M = 15.72, SD = 26.3; M = 37.00, SD = 32.9, respectively),  $F(1.38) = 15.24$ ,  $p < .001$ .

**Do you have any additional comments you would like to make about First Link or the Alzheimer Society?**

- *Very supportive and collaborative.*
- *Very positive feedback from families about First Link.*
- *The referral process is awesome - it has really increased the number of folks who have contact with the Alzheimer Society - giving pamphlet and suggesting they call (over and over again) wasn't working.*
- *Information on community resources is not useful: there aren't any. Waste of time and money.*
- *Timely, efficient service enhancing support and services and knowledge to clients with Alzheimer's / dementia.*
- *The more support for patients with dementias and their families, the better.*
- *The First Link program has been of immense value to me as a social worker. I have made many referrals with exceptionally good feedback from the clients/ families referred. They have appreciated the emotional support, proactive ideas and linkages with other community resources. First Link has been very responsive, providing feedback on all referrals. I truly feel this is an ESSENTIAL service in our community. Highly recommended. I recommend First Link to all clients/ families dealing with dementia. Having cared for a parent with dementia, it would have been invaluable to have had this resource available at that time. Referred clients comment on timely, respectful response, support, a good conduit to resources through the Alzheimer Society.*
- *Recently had change in First Link person. Changed the service model. Also budget reduced- less service/ less contact/ less knowledge.*
- *Extremely satisfied - except for one thing. I see patients with dementia, investigate, diagnose and treat meant, before I refer them. I do not think they then all need to be referred again to the psychogeriatric team. I only refer complex patients to them. Patients who have had contact with First Link all seem to come away believing they need a psychogeriatric referral. First Link was much more useful when the designated coordinator was available.*
- *Very happy with First Link. Huge help for the family members. First Link accepts and activates referrals quickly.*
- *Community Support services - I'd like to know more about the specifics of these. Great resource. My biggest difficulty lies with encouraging family/ caregivers to access First Link and related services. I'm not sure if they hesitate because of denial of the diagnosis, or they already feel overwhelmed by day-to-day duties and can't juggle one more contact. I'd appreciate your suggestions re: how to motivate families/ patients to contact First Link.*
- *I think the Alzheimer Society does excellent work and that First Link be incorporated into their overall programming. I understood that this program was launched as a pilot study originally I feel its services could be meshed into the overall services that the Alzheimer Society offers. I wondered if there was a bit of a disconnect between the awareness services offered by First Link and what was already being done by the Alzheimer Society. Staff in both the First Link program and with the Alzheimer Society main office have been great to work with! It is wonderful to find such willing and helpful partners!*
- *An excellent initiative!*

- *I don't know much about First Link. I do mention Alzheimer Society to patients and families and encourage them to make contact.*
- *I only use First Link as an educational/support tool for patients/families. It does an excellent job in that respect.*
- *Good program. I hope it will be continued to be funded.*
- *A great support*
- *The Alzheimer Society in my area is proactive and involved. Our relationship is important in cross referring and the PEC has attended clinics educating care givers who take the next step toward support group or other supports. We depend on the expertise and support of this wonder group. (Huron)*
- *Keep up the good work*
- *Wonderful work, need more resources*
- *the percentage numbers previously were based on the pts I tend to see within the FHT*
- *I find the people in the Ottawa office so approachable, helpful and open to suggestions. They are a pleasure to work with.*
- *All chapter should receive core funding for this much needed program.*
- *Great services, keep the good work!*
- *The Alzheimer Society remains an invaluable resource for the community. The First Link program is a reflection of the great work this organization does.*
- *They are a very organized, supportive and collaborative site.*
- *First link is a wonderful service. I refer the majority of my patients there, especially when they are first diagnosed with a dementia. The fact that first link will call them I think very much increases the number of patients/caregivers that actually have contact with the society. The availability of continuity of care is excellent as well.*
- *We find it very helpful to be able to refer our patients and families we have recently diagnosed - thank you!*
- *Should be available country wide*
- *We will be using First Link services more as time goes on. After they first introduced themselves we never heard from them for a long time so the fire burned out so to speak. With GiiC and Dr. Clarke now in the mix I feel we could have a resurgence of First Link referrals.*
- *I had an experience lately which showed me the power of linkages in community agencies. About a year ago, I gave an in-service at a retirement home. As a result of this, the DOC contacted our local First Link coordinator to arrange for more education for her staff on supporting families. This month, I learned that client's family had been attending family education sessions at that facility even though their loved one did not live in the facility. As it turned out, they needed to move the person to a facility on an urgent basis and because of their experience at the facility, chose this place, and felt more comfortable because of their previous connections. I have been very impressed by and grateful for the First Link services. I feel that there is a safety net, a place where families can be helped to be part of the caregiving process in a mutual way, equipped with information which increases their confidence, decreases the sense of helplessness which many feel, and comforted with knowing they are not alone.*