Alzheimer Society Impact:

Translating the attitudes and experiences of care partners and persons living with dementia into quantifiable measures

Elgin-St. Thomas
Grey-Bruce
Huron County
London and Middlesex
Oxford
Perth County

This publication is also available online at: www.brainscan.ca/alzheimer-report/

Alzheimer Society
Ontario
Alzheimer Society
London and Middlesex
Western Brains CAN
Transforming brain research.
This survey analysis for the Alzheimer Society of Ontario (ASO) and the Alzheimer Societies in the South West Local Health Integration Network (SW LHIN) was provided by BrainsCAN, a neuroscience research initiative at Western University that aims to transform the way brain diseases and disorders are understood, diagnosed and treated.

Photo on cover provided by the Alzheimer Society London and Middlesex.

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Alzheimer Society Impact: Translating the attitudes and experiences of care partners and persons living with dementia into quantifiable measures

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To say that dementia is a complex condition is an obvious understatement. For people living the journey, the challenges presented by dementia are life altering. For those organizations that serve these families and individuals, the complexity and challenge presents itself in the effectiveness of program delivery.

Are we positively impacting our clients? Are we being as effective as we can be? Are there areas of our programming where there are gaps?

This pilot survey project between Western’s BrainsCAN and the Alzheimer Society helps answer those questions and brings a clarity to our role as service providers that we haven’t had before. And while it is gratifying from an operational perspective to gain such a viewpoint, the greater reward is the further positive impact upon our clients in our program delivery.

– Carol Walters
CEO, Alzheimer Society London and Middlesex
Introduction

Over 240,000 Ontarians live with dementia today, a number that is expected to double within the next twenty years.¹

What is dementia?

Dementia refers to a set of symptoms caused by disorders affecting the brain. Symptoms can include memory loss, difficulties with thinking, problem-solving or language, and changes in mood or behaviour. For those with dementia, symptoms are often severe enough that they affect a person’s ability to perform everyday activities.²

Dementia doesn’t only affect those with the disease, it also impacts care partners, family members and friends.³ Care partners are those who provide ongoing care and assistance to family members and friends diagnosed with dementia. The support provided by these care partners is done without pay.

The costs for caring for someone with dementia are high. It is estimated that from 2008-2038, dementia will cost Ontario close to $325 billion.⁴ Costs can include health care usage such as more prescriptions, and often more emergency department visits or hospitalizations for preventable issues. Those with dementia and their care partners can also incur lost wages or increased out-of-pocket expenses.⁵ Care partners may also pass up promotions, or reduce their work to part-time hours, often at the height of their career. This impacts Ontario’s greatest economic advantage: our highly trained, highly educated workforce.

For many people, living well means living independently or in their homes, and participating in their community for as long as possible.⁶ It’s important that people have access to the support and services they need in order to live well with the disease.

Pilot Project

In 2018, the Alzheimer Society London and Middlesex (ASLM) and BrainsCAN first developed a pilot project to analyze the Society’s existing client survey. BrainsCAN, Western University’s neuroscience research initiative, used its expertise in research reporting to review a previously conducted ASLM client survey, provide an analysis and make recommendations for future survey practices that could quantitively support ASLM’s mission. The final results revealed that the Alzheimer Society’s services were a lifeline to its clients, yet more could be done to assist the organization in delivering those services to people living in London and Middlesex.

Those report findings led to a formal partnership with BrainsCAN, ASLM, and the Alzheimer Society of Ontario (ASO) to bring BrainsCAN’s analytical survey method to six Alzheimer Societies located in the South West Local Health Integration Network (SW LHIN).
Executive Summary

Are Alzheimer Society programs benefiting their clients and the healthcare system?

The Alzheimer Society’s First Link® Program connects people living with dementia and their care partners to the information, supports and services they need as early as possible and throughout the progression of the condition. The Societies provide resources and services to more than 85,000 clients across Ontario. With 29 Societies across the province, the Alzheimer Societies are often one of the first places care partners and those living with dementia go after a dementia diagnosis.

While the Alzheimer Society has anecdotal evidence of their positive impact on families, the questions remained – how do the majority of care partners and those living with dementia engaged with Alzheimer Society programs feel about their local organization, and what impact do these programs have on the healthcare system in southwestern Ontario?

To assist the Alzheimer Societies in answering these questions, Western’s BrainsCAN prepared a survey that was distributed to clients of the six Alzheimer Societies located within the SW LHIN during the summer of 2019. The Societies included:

- Alzheimer Society of Elgin-St. Thomas
- Alzheimer Society of Grey-Bruce
- Alzheimer Society of Huron County
- Alzheimer Society London and Middlesex
- Alzheimer Society of Oxford
- Alzheimer Society of Perth County

The survey found that an overwhelming percentage of those who took part in the survey had positive attitudes toward their Alzheimer Society programs and services. This was reported for everyone – including those who had been engaged with their local Society for less than a year, to those who had been engaged for more than ten years, indicating that Alzheimer Society programs and services have an immediate and long-lasting impact.

The survey also found that a positive attitude towards the Alzheimer Society increased for care partners if the person they support also attended, or at one point attended, Alzheimer Society programs. This demonstrates that services for those living with dementia are as beneficial to care partners as they are for those diagnosed.

In addition, the results also found that Alzheimer Societies have an impact on care partners and those living with dementia in the following ways: **extended time living at home** and **information leading to crisis avoidance**.

Furthermore, the survey discovered that care partners and those living with dementia were also affected by: **quality of life** and **impact on employment productivity**.
Overall Report Data

The survey was sent to care partners and those living with dementia who are clients, or previous clients, of the six Alzheimer Societies in the SW LHIN.

In total, 521 individuals completed the survey. Of those 521, 457 were care partners and 64 were persons living with dementia. Care partners who answered the survey were 78% female, while 68% of those living with dementia who filled out the survey were male.

Survey participants were asked how long they had been engaged with their closest Alzheimer Society. Of the respondents, 25% indicated they had less than one year of engagement with their local Society, falling into the category of a “new” client.

The level of care required was different for each group. Care partners noted that the person they were supporting with dementia required mild to moderate care in 54% of the responses, and full assistance in 38% of the responses. Those living with dementia who filled out the survey were equally divided by living independently or requiring mild to moderate care.

89% of respondents felt positively about their local Alzheimer Society.

Overall, the outlook toward the Alzheimer Societies was overwhelmingly positive, with 89% indicating they had a positive attitude toward their local Alzheimer Society.
<table>
<thead>
<tr>
<th></th>
<th>Care Partner</th>
<th>Person Living with Dementia</th>
<th>All</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>No.</td>
<td>%</td>
<td>No.</td>
</tr>
<tr>
<td>Respondents</td>
<td>457</td>
<td>87.7%</td>
<td>64</td>
</tr>
<tr>
<td>Age Groups</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;30</td>
<td>0</td>
<td>0%</td>
<td>0</td>
</tr>
<tr>
<td>30-39</td>
<td>8</td>
<td>1.8%</td>
<td>0</td>
</tr>
<tr>
<td>40-49</td>
<td>25</td>
<td>5.6%</td>
<td>0</td>
</tr>
<tr>
<td>50-59</td>
<td>76</td>
<td>17.1%</td>
<td>4</td>
</tr>
<tr>
<td>60-69</td>
<td>131</td>
<td>29.5%</td>
<td>8</td>
</tr>
<tr>
<td>70-79</td>
<td>155</td>
<td>34.9%</td>
<td>27</td>
</tr>
<tr>
<td>&gt;80</td>
<td>49</td>
<td>11%</td>
<td>21</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Men</td>
<td>101</td>
<td>22.2%</td>
<td>42</td>
</tr>
<tr>
<td>Women</td>
<td>352</td>
<td>77.5%</td>
<td>19</td>
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<tr>
<td>Prefer not to answer</td>
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<td>0.2%</td>
<td>1</td>
</tr>
<tr>
<td>Engagement Duration</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Returning (&gt;1 year)</td>
<td>310</td>
<td>74.5%</td>
<td>42</td>
</tr>
<tr>
<td>New (&lt;1 year)</td>
<td>106</td>
<td>25.5%</td>
<td>14</td>
</tr>
<tr>
<td>Engagement Volume in Last Year</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1-4 times</td>
<td>180</td>
<td>41.4%</td>
<td>13</td>
</tr>
<tr>
<td>5-9 times</td>
<td>79</td>
<td>18.2%</td>
<td>14</td>
</tr>
<tr>
<td>10-14 times</td>
<td>68</td>
<td>15.6%</td>
<td>6</td>
</tr>
<tr>
<td>15-19 times</td>
<td>34</td>
<td>7.8%</td>
<td>9</td>
</tr>
<tr>
<td>more than 20 times</td>
<td>74</td>
<td>17%</td>
<td>16</td>
</tr>
<tr>
<td>Level of Care Required</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>PLWD is Independent</td>
<td>37</td>
<td>8.3%</td>
<td>30</td>
</tr>
<tr>
<td>PLWD needs mild to moderate care</td>
<td>241</td>
<td>54.3%</td>
<td>31</td>
</tr>
<tr>
<td>PLWD needs full Assistance</td>
<td>166</td>
<td>37.4%</td>
<td>-</td>
</tr>
<tr>
<td>Supported Person Involved</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>185</td>
<td>41.8%</td>
<td>-</td>
</tr>
<tr>
<td>No longer</td>
<td>80</td>
<td>18.1%</td>
<td>-</td>
</tr>
<tr>
<td>No</td>
<td>178</td>
<td>40.2%</td>
<td>-</td>
</tr>
<tr>
<td>Attitude towards AS</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Positive</td>
<td>396</td>
<td>90%</td>
<td>48</td>
</tr>
<tr>
<td>Neutral</td>
<td>14</td>
<td>3.2%</td>
<td>4</td>
</tr>
<tr>
<td>Critical</td>
<td>30</td>
<td>6.8%</td>
<td>6</td>
</tr>
</tbody>
</table>
Report Findings

Responses in the survey revealed a variety of information on how clients of the Alzheimer Society feel about the programs and services offered by Societies in the SW LHIN, and what impact those programs have on the area’s healthcare system.

Demographics:

When reviewing the number of new clients, the results found that 25% of survey respondents had participated in Alzheimer Society programming for less than a year. This suggests that there is a continued need for Alzheimer Society programs and that the Society’s client base is continuing to grow.

![Figure 3: New Alzheimer Society Clients](image)

**25%**

joined as an Alzheimer Society client in the last year

*Note that the number of new clients varies from Society to Society. This number is also based on those clients who completed the survey.

Attitude toward the Alzheimer Societies:

The survey questions relating to attitudes toward the Alzheimer Societies were separated into four categories. These categories focused on the Alzheimer Society’s ability to provide support in the following areas:

- **Learning and informational**: The Alzheimer Societies provide information about dementia to help care partners and those with dementia understand the neurological disease(s).
- **Emotional support**: The Alzheimer Societies provide emotional support (counselling, sharing stories, etc.) to care partners and those living with dementia.
- **Capacity for care**: The Alzheimer Societies help care partners and those living with dementia increase their skills in living well with the disease.
- **Interventional care**: The Alzheimer Societies support care partners and those living with dementia through crisis situations.

While care partners and those living with dementia benefited from all four categories, they had consistently positive attitudes toward the informational and emotional support provided by the Alzheimer Societies.

Care partners also had a more positive view of Alzheimer Society programming if the person they’re supporting is currently involved, or was once involved, with the Alzheimer Society.
General Overview on Quality of Life:

A care partner’s role is complicated and can include a number of tasks such as providing assistance with transportation and healthcare, emotional and physical support during crises, and assistance around the home. The role often generates stress that stems from these and other caregiving duties.  

To learn how care partners and those living with dementia viewed their experiences, they were asked for their level of agreement on statements regarding quality of life. The most evident trend was connected to the quality of life for care partners.  

After splitting the data into three general levels of dementia that require care - independent stage, mild to moderate and full assistance - the findings show that quality of life for the care partner drops once the person he/she is supporting moves into the mid to moderate stages of dementia.  

According to the survey, the biggest difference in how care partners viewed quality of life between independent and mid to late stages of dementia focused on the question, “There is time and energy for self-care and the pursuit of fun activities.” The dramatic drop in quality of life for this specific question could be due to the increasing responsibility and complexity of caregiving tasks as the supported person’s symptoms become more evident, leading to care partners having less time to focus on themselves.  

Overall, the survey demonstrates that being a care partner is a challenging role, and that quality of life of the care partner is impacted as the individual living with dementia progresses with the disease. As care partners play an invaluable role, it’s essential that support is provided to them to ensure they can still live well while caring for someone living with dementia.

![Figure 4: Survey Results - Care Partner Quality of Life](image-url)
Employment Impact:

Caring for someone with dementia, or receiving a diagnosis of dementia, can have an impact on a person’s ability to work. To better understand how employment status and work productivity are affected by a dementia diagnosis, respondents were asked to verify their current employment status.

Sixty-nine per cent of care partners were retired and 93% of those living with dementia identified as retired. Fifteen per cent of those living with dementia indicated that their symptoms had an impact on their decision to retire.

Eighteen per cent of care partners who were retired indicated that their caregiving duties had influenced their decision to retire. However, age had an influence on this decision. After separating the retired care partners into age demographics, it was clear that age influenced whether a care partner’s role impacted the timeline for his/her retirement.

While 0% of care partners aged 80 years and older retired due to caregiving duties, 70% of care partners in their 50s retired in part because of their care partner role. This indicates that the older care partner population had already retired before their caregiving duties began.

![Figure 5: Survey Results - Retired Care Partners by Age Group](image)

*Disclaimer: Note the age of the care partner indicated in this graph represents the age of the respondent when he/she filled out the survey.

My wife, Ruth was diagnosed with vascular dementia in January of 2018. I was teaching ESL full time in the elementary schools when she was diagnosed. To attend more appointments and an education program at the Alzheimer Society, I started working part time for three months. As Ruth continued to decline, I decided to retire in March, which was about a year earlier than planned.

– Maggie, care partner to her wife Ruth
Does being a care partner or having dementia have a negative impact on work productivity?

In some cases, those who are care partners or those diagnosed with dementia are still at an age where working is necessary. For respondents who are employed, they were asked if their role as a care partner or their dementia symptoms negatively impacted their work productivity.

Fifty per cent of employed care partners noted their caregiving duties had negatively impacted their ability to be productive at work. On average, they indicated missing 10 days of work per year to engage in caregiving responsibilities (based on estimates by the employed care partners on their days of missed work).

For every 1,000 care partners, which includes those who are retired, employed or unemployed, these 10 days of missed work result in an annual loss of $232,000 in productivity. However, these 10 days do not take into account the reduced productivity from emotional strain care partners endure when they’re at work, suggesting that $232,000 is the base cost of reduced productivity for care partners.

For every 1,000 care partners, an annual loss of $232,000 is incurred by missed days of work by those employed.

<table>
<thead>
<tr>
<th>Employment Type</th>
<th>Care Partner</th>
<th>Person with Dementia</th>
<th>All</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>No.</td>
<td>%</td>
<td>No.</td>
</tr>
<tr>
<td><strong>Unemployed</strong></td>
<td>4</td>
<td>0.9%</td>
<td>0</td>
</tr>
<tr>
<td><strong>Employed</strong></td>
<td>100</td>
<td>22.3%</td>
<td>2</td>
</tr>
<tr>
<td><strong>Retired</strong></td>
<td>309</td>
<td>68.8%</td>
<td>55</td>
</tr>
<tr>
<td><strong>Other</strong></td>
<td>31</td>
<td>6.9%</td>
<td>1</td>
</tr>
<tr>
<td>Prefer not to Answer</td>
<td>5</td>
<td>1.1%</td>
<td>1</td>
</tr>
</tbody>
</table>

*see Methodology, page 16 for more information*
Extended Time at Home:

Living well for someone who is diagnosed with dementia often corresponds to living at home for as long as possible. With an aging population and an increasing demand on long-term care facilities, living at home also benefits Ontario’s healthcare system that is overwhelmed by demand with limited resources.8

The Alzheimer Societies provide information and resources to assist care partners and those living with dementia to stay at home longer. Seventy-five per cent of care partners and those living with dementia reported that the Alzheimer Society helped them increase their skills as care partners, or increased their ability to better manage living with dementia. This 75% were asked if Alzheimer Society programs increased their confidence in providing care at home. The survey found that 72% of these respondents were more confident living at home, or providing care at home, due to the Alzheimer Society’s involvement.

You think you understand the disease, but we learned so much attending programs with the Alzheimer Society. When I attend group sessions, other care partners share their strategies and I’ve seen how to manage situations in different ways. I’ve learned from others’ journeys and that helps us handle our own.

– Heather, care partner to her husband Charlie

Figure 8: Level of Confidence at Home

72% of care partners and those living with dementia who reported increased skills developed by Alzheimer Society programs, were more confident living at home because of these programs.
“She’s at a stage now where I don’t think she’d be at home – we wouldn’t be living together still – if it hadn’t been for our experience with the Alzheimer Society. It’s given us a little more time together.”

– Tony, care partner to his wife Susan

Care partners who had increased confidence providing care were asked to estimate the increased amount of time the Alzheimer Society support allowed them to provide care at home. Although preliminary, the data suggest that Alzheimer Society support increases their clients’ ability to live at home for an additional three years, resulting in considerable cost savings for Ontario’s healthcare system.

With an Ontario budget investment of $54,730* per year for one long-term care bed, $164,190 was saved for each person who indicated an additional three years of time spent living at home. This time at home creates capacity by ensuring beds are allocated to those who need them most.

Providing support for care partners and those living with dementia to live at home longer has a societal impact – not only does it create cost savings for the healthcare system, but it also allows those living with dementia to live independently for longer.

*see Methodology for more information
Crisis Avoidance

Crises often arise when a stressor becomes overwhelming or unmanageable requiring immediate action. Often for those living with dementia, crises result in a hospital visit or acute care intervention.\(^9\)

The Alzheimer Society works with care partners and those living with dementia to prevent crises and prepare for when a crisis occurs. This intervention is working. Over 50% of care partners who were experiencing crises agreed that the Alzheimer Society helped them avoid a crisis.

**Figure 9: Crisis Avoidance**

- **53.1%** care partners
- **51.8%** persons living with dementia

Percentage of care partners and those living with dementia who reported that the Alzheimer Society helped them avoid crises

Care partners indicated that the Alzheimer Society’s support helped them avoid an average of 2.7 crises each year with 1.4 of those crises likely leading to hospital care. For every 1,000 care partners, 531 avoided an average of 1.4 hospital crises per year, saving the healthcare system $4.2 million annually* (based on estimates by care partners on perceived crisis avoidance).

Overall, the Alzheimer Society provides valuable resources and services to care partners and those living with dementia when it comes to crisis avoidance.

*see Methodology for more information
Methodology

An initial analysis of ASLM’s client survey in 2018 led to a collaborative survey development by BrainsCAN, ASLM and ASO to develop a survey suitable for the six Alzheimer societies in SW LHIN. The survey was designed to be agile and pose follow-up questions. It also included two versions – one for the person with dementia and another for the care partner (care partner was not defined and was at the discretion of those filling out the survey).

Distributed to Alzheimer Society clients in August 2019, 595 care partners and those living with dementia in southwestern Ontario submitted the survey. The exact number of completed surveys were 521 – with 457 completed by care partners and 64 by those living with dementia.

Western’s online survey tool, Qualtrics, was used. A paper version of the survey was also made available. Once the survey closed, all of the paper data was inputted into Qualtrics and the results were exported into SPSS, a relational database and statistical analysis software program.

Demographic data was represented as indicated in the survey unless subgroup respondents needed to be pooled to allow meaningful comparisons. For example, the age group of younger than 30 and 30-49 were pooled to a single “under 50” group for certain analyses. This was done to ensure a large enough pool of respondents in that age group to extract meaningful data.

The “Attitude towards the Alzheimer Society” was taken from the survey question, “On a scale of 1 to 10, how likely are you to recommend the Alzheimer Society to a family member, friend or colleague?” Scores of 8-10 were deemed to reflect a positive attitude toward the Alzheimer Society, while 7 was deemed to be neutral and 0-6 was labelled as critical of the Alzheimer Society.

New participants were noted as “new” when their engagement duration was less than one year, as those individuals would not have responded in the previous annual reporting period.

Weighted mean of agreement values were calculated from [(per cent respondents)*(weight of agreement)], where strongly disagree was weighted at -2, disagree at -1, neutral at 0, agree at 1 and strongly agree at 2.

Note: Some data was collected but not included in the full analysis report. These findings were operational in nature and did not have an impact on the respondent’s experience with the Alzheimer Society.

There are three incidences where perceived cost/value calculations were performed:

• The value of lost productivity used the proportion of employed care partner respondents indicating a negative effect on productivity, their estimate of days lost per year, and the cost of a lost day of $207.75 (based on Statistics Canada’s average wage of $27.70 per hour for an average workday of 7.5 hours).

• The value of extended time at home used the proportion of care partner respondents indicating engagement extending their confidence in providing care at home, their estimate of extended time, and provincial contribution toward long-term care beds of $54,730/bed/year (based on the 2018 Ontario Budget, LTCH Level-of-Care Per Diem Funding Summary).

• The value of crisis avoidance used the proportion of care partner respondents indicating engagement helped them avoid a crisis, their estimate of number of avoided crisis per year likely to have needed acute care, and the cost of an acute hospital visit of $5,727 (based CIHI’s calculated cost for the SW-LHIN).

For the full report, please visit: www.brainscan.ca/alzheimer-report/
Conclusions

Alzheimer Society Impact:

The Alzheimer Society client survey revealed valuable information about how Society programs are utilized. It also discovered that Society programming has a wider societal impact on the healthcare system in areas located in southwestern Ontario.

Based on feedback from more than 500 care partners and those living with dementia, it’s clear that Alzheimer Societies provide valuable programs and services for those affected by the disease. More than 89% of respondents had a positive attitude towards their local Alzheimer Society.

The survey revealed that 25% of care partners and those living with dementia were new clients to the Alzheimer Societies – they began using programs and services provided by the Societies within the year.

While the Alzheimer Society delivers a wide variety of services, care partners and those living with dementia had consistently positive attitudes toward programs that offered information about the disease and emotional support.

The Alzheimer Society’s programs and services also benefit southwestern Ontario’s healthcare system. Care partners and those living with dementia reported feeling more confident living at home due to Alzheimer Society programs and training. In addition, Alzheimer Society information and training helped care partners avoid crisis situations or know what to expect in the event of a crisis. According to the survey, these Alzheimer Society interventions led to less demand on Ontario’s healthcare system in the southwest with potential increased savings for hospitals located in the SW LHIN.

Other Findings:

The survey also found that care partners still employed were negatively impacted by caregiving duties when it came to work productivity. Employed care partners reported 10 days of missed work days per year due to caregiving responsibilities. This number results in an annual loss of $232,000 for every 1,000 care partners.

Care partners also reported having a declining quality of life as the person with dementia experiences disease progression. This further evidences the challenges experienced by care partners who are caring for someone living with dementia.

In conclusion, Alzheimer Society programs and services benefit those living with dementia, their care partners, but also the healthcare system in southwestern Ontario. It’s clear from the responses of care partners and persons living with dementia that the more information and support they have from the Alzheimer Society, the less likely they are to rely on other aspects of the healthcare system. Not only does this save time and money, but it also ensures care partners feel more confident assisting someone living with dementia.
Acknowledgements

Western’s BrainsCAN, the Alzheimer Society London and Middlesex, and the Alzheimer Society of Ontario would like to thank the following for their assistance with the survey and report:

- **Clients of the six Alzheimer Societies in the South West Local Health Integration Network** who answered the survey.

- **Heather, Tony and Maggie**, care partners who shared their experiences and provided quotes for the report.

- **Western University’s BrainsCAN Executive Committee** for reviewing the report.

- **Christine Poier**, Acting Site Manager of the Alzheimer Society Elgin-St. Thomas; **Stephen Musehl**, Executive Director of the Alzheimer Society of Grey-Bruce; **Cathy Ritsema**, Executive Director of the Alzheimer Society of Huron County; **Shelley Green**, Executive Director and **Leanne Turner**, Managing Director of the Alzheimer Society of Oxford; and **Debbie Deichert**, Executive Director and **Sheri Gilhula**, First Link/Education Coordinator of the Alzheimer Society of Perth County for distributing the survey to Alzheimer Society clients and providing insightful contributions to the report.

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- **Christina Stergiou-Dayment**, Program Director, First Link for leading the project.

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- **Maggie MacLellan**, Communications Specialist at Western University’s BrainsCAN for leading the project and writing the summary report.

- **Carol Walters**, CEO of the Alzheimer Society London Middlesex for leading the project.


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