

Alzheimer Society Impact

Executive Report

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



Western BrainsCAN

Transforming brain research.

This survey analysis for the Alzheimer Society of Ontario (ASO) and the Alzheimer Societies in Ontario (ASiO) 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. BrainsCAN is supported by an investment from the Government of Canada through the Canada First Research Excellence Fund (CFREF). Survey data collection and analysis for this report took place in 2021.

brainscan.uwo.ca

Permission to Reproduce

The information in this publication is covered by the provisions of the Copyright Act, and by other Canadian laws, policies, and regulations. Except as otherwise specifically noted, the information in this publication may be reproduced, in part or in whole and by any means, without charge or further permission from Western's BrainsCAN provided that best efforts are used to ensure the accuracy of the information reproduced, that BrainsCAN, the Alzheimer Societies in Ontario, and the Alzheimer Society of Ontario are identified as the source institutions, and that the reproduction is not represented as an official version of the information reproduced, nor as having been made in affiliation with, or with the endorsement of, BrainsCAN, the Alzheimer Societies in Ontario, and the Alzheimer Society of Ontario.

©2021 Western's BrainsCAN

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

All rights reserved.

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



CANADA
FIRST
RESEARCH
EXCELLENCE
FUND

APOGÉE
CANADA
FONDS
D'EXCELLENCE
EN RECHERCHE

Table of Contents

Introduction	4
Overview	6
Report findings	7
• Demographics and Attitudes	8
• COVID-19 Impact on Alzheimer Society Care	10
• Quality of Life Assessment	11
• Employment Impact	12
• Extended Time at Home	14
• Distress Intervention	15
• Care Partner Support	16
• Long-Term Care	18
Methodology	19
Conclusions	20
Acknowledgements	21
References	22

Introduction

Dementia is regarded as one of the most significant health crises of the 21st century. Every three seconds, someone in the world develops dementia.¹ Over a quarter of a million Ontarians live with dementia today, a number that will only increase as the province's population ages.² Dementia does not only affect those living with the condition: care partners, friends, and family members are also impacted, and the societal impact of dementia extends even further.



What is dementia?

Dementia is a general term that covers a range of conditions caused by disorders affecting the brain. While Alzheimer's disease is the most common form of dementia, there are other types that can have similar and overlapping symptoms.³ Symptoms can include memory loss, difficulties with thinking, problem-solving or language, and changes in mood or behaviour. For people living with dementia, these symptoms may become severe, affecting a person's ability to perform everyday activities.⁴

The worldwide economic impact of dementia is staggering, with annual global costs totalling more than \$1.6 trillion.⁵ In Ontario, it is estimated that from 2008-2038, dementia will cost the province close to \$325 billion.⁶ Costs associated with dementia can be attributed to a variety of factors, including, but not limited to:

- **medical care**, such as prescriptions and increased emergency department visits or hospitalizations
- **informal, unpaid care** provided by a family member or friend
- **social care**, or in-home assistance delivered by community care professionals¹

People living with dementia and their care partners may also incur costs related to lost wages and high out-of-pocket expenses: across Canada, care partners to people living with dementia spend \$1.4 billion of their own money every year.⁷ Care partners may also pass up work promotions or reduce their full-time work hours to part-time, often at the height of their career to provide informal care. Such changes to employment and income have a negative impact on the care partner, leading to increased levels of stress and burnout. In turn, this may result in greater health issues for the care partner, and the inability to care for the person living with dementia leading to more frequent hospitalizations or early admission to long-term care.

The financial and opportunity costs associated with caregiving are felt disproportionately by women. Despite accounting for a little over half of the overall number of care partners in Canada, women are twice as likely as men to spend over 20 hours per week on their caregiving responsibilities.⁸

For many people, living well means living independently at home and staying engaged within the community for as long as possible.¹⁰ The Alzheimer Society provides Ontarians living with dementia and their care partners with support through local programs and services. With 27 Societies across the province, resources and services are delivered to more than 101,785 clients – helping individuals of all ages and stages of dementia continue to live well.



27^{*}
Societies across
Ontario **with**
101,785+
clients accessing
resources and services

Pilot and South West Project

In 2018, the Alzheimer Society London and Middlesex (now known as the Alzheimer Society Southwest Partners) and BrainsCAN first developed a pilot project to analyze the Society's existing client survey. BrainsCAN used its expertise in research reporting to review a previously conducted Alzheimer Society London and Middlesex client survey, provide an analysis, and make recommendations for future survey practices that could quantitatively support the Society's mission. Final results revealed that the Alzheimer Society's services were a lifeline to its clients; however, more could be done to assist the organization in delivering their services to people living in the London and Middlesex region.

Findings from the report led to a formal partnership in 2019 with BrainsCAN, the Alzheimer Society London and Middlesex, and the Alzheimer Society of Ontario to bring BrainsCAN's analytical survey method to six Alzheimer Societies in the Home and Community Care Support Services South West area.

A BrainsCAN report for the six Alzheimer Societies was completed in December 2019. With this new understanding of the impact of their work, the survey was extended Ontario-wide to 29 Alzheimer Societies in 2021. This report details the results from a survey completed by clients of Alzheimer Societies across Ontario.

**At the time of survey distribution, the total number of Alzheimer Societies across Ontario was 29. Since that time, three Alzheimer Societies have unified, resulting in a total of 27 Alzheimer Societies across the province.*

Overview

The Alzheimer Society provides a wide array of programs, services, and social supports across local Societies. This support is provided as early as possible and continues throughout the progression of the condition. The purpose of this work is to help care partners and those living with dementia find hope, relief, and support throughout their journey with dementia.

While Alzheimer Societies across Ontario had anecdotal evidence of their positive impact on families, the following questions remained:

What is the impact of Alzheimer Society programming and services on care partners and those living with dementia in Ontario?

Does this impact have a positive effect on the Ontario healthcare system?

In 2021, an Ontario-wide survey conducted by BrainsCAN was distributed to clients of 29 Alzheimer Societies across the province. Results found that an overwhelming percentage of those who filled out the survey had positive attitudes toward their local Alzheimer Society programs and services. This was reported by everyone—including those who had been engaged with their local Society for less than one year to those who had been engaged for more than seven years—demonstrating that Alzheimer Society programs and services have both an immediate and long-lasting impact.

Results also found that the Alzheimer Society has an impact on care partners and those living with dementia by prolonging time lived at home and providing distress intervention. In addition, the survey shed light on the quality of life and impact on employment productivity for care partners and those living with dementia. Results indicate that Alzheimer Society programs and services are a cost-benefit to the provincial healthcare system, alleviating pressure on hospital and long-term care capacity.

“

I feel supported and cared for on a mental health level that keeps me grounded and helps guide me in my mission to help my dad. Because of the Society, I know I'm doing the right things and I have someone who knows all the ins and outs of "the system" and can help me navigate, which gives me confidence in what I'm doing.

– care partner

”

Report Findings

Report Data and Findings

In total, 2,184 individuals completed the survey. Of those, 1,912 were care partners and 272 were persons living with dementia. When it came to gender, care partners who answered the survey were predominantly women at 72.6%, whereas an equal number of those living with dementia were women and men.

Survey Respondent Information



Certain demographic choices were provided in the survey (e.g. transgender and two-spirited), but not shown in the analysis due to lack of response. Gender breakdown figures may not add up to 100% as some survey respondents preferred not to answer.

Survey participants were asked how long they had been engaged with their local Alzheimer Society. Of the respondents, 38.1% indicated they had less than one year of engagement, falling into the category of a new client. This figure suggests there is a continued and growing need for Alzheimer Society programs to serve new clients across the province.

The level of care required was different for each group. In 42.6% of responses, care partners indicated the person they support needed some assistance, and an additional 50.9% of care partner respondents said their supported person required a lot of assistance. Those living with dementia were independent in 36.6% of the responses and required some care in 46.9% of the responses from this group.

Note: Those living with dementia who require extensive support may be less likely to complete the survey. The low representation among this group is not reflective of the current population of those living with dementia.

Support Categories

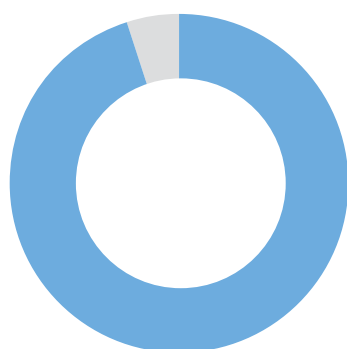
To better understand how the Alzheimer Societies provide support to care partners and those living with dementia, their programs and services were separated into four categories.

- **Learning and informational:** The Alzheimer Societies provide information about dementia to help care partners and those living with dementia understand the brain condition and what to expect.
- **Emotional support:** The Alzheimer Societies provide emotional support (counselling, social engagement, 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 condition.
- **Distress Intervention:** The Alzheimer Societies support care partners and those living with dementia through times of distress.

Attitude toward the Alzheimer Societies

When evaluating how respondents felt about their local Alzheimer Society, the survey asked respondents how likely they were to recommend Alzheimer Society services to others.

Overall, the outlook toward the Alzheimer Societies was overwhelmingly positive, with 97.6% of respondents indicating they were likely to recommend Alzheimer Society services to others of which 78.2% said they were very likely to recommend.



97.6%
likely to
recommend
Alzheimer Society
services



78.2%
very likely to
recommend
Alzheimer Society
services

Respondent Demographic Information

	Care Partner		Person Living with Dementia	
	No.	%	No.	%
Respondents	1,912	87.5%	272	12.5%
Age Groups	No.	%	No.	%
<30	9	0.5%	0	0.0%
30-39	30	1.6%	0	0.0%
40-49	112	5.9%	2	0.8%
50-59	384	20.3%	8	3.3%
60-69	518	27.4%	31	12.8%
70-79	564	29.8%	113	46.7%
80-89	259	13.7%	81	33.5%
Over 90	15	0.8%	7	2.9%
Gender	No.	%	No.	%
Man	446	26.0%	119	49.0%
Woman	1245	72.6%	123	50.6%
Prefer not to Answer	23	1.3%	1	0.4%
Engagement Duration	No.	%	No.	%
Less than 3 months	274	15.4%	48	19.8%
4-12 months	388	21.9%	58	24.0%
1-3 years	802	45.2%	106	43.8%
4-6 years	251	14.1%	20	8.3%
More than 7 years	59	3.3%	10	4.1%
Engagement Duration Summarized	No.	%	No.	%
Returning (>1 year)	1109	63.3%	130	56.3%
New (<1 year)	643	36.7%	101	43.7%
Frequency of Use in Last Year	No.	%	No.	%
1-4 times	849	47.9%	116	48.9%
5-9 times	413	23.3%	46	19.4%
10-14 times	212	12.0%	27	11.4%
15-19 times	76	4.3%	16	6.8%
More than 20 times	222	12.5%	32	13.5%
Level of Care - Person Living with Dementia	No.	%	No.	%
Is independent	123	6.5%	95	36.3%
Needs some support	807	42.6%	123	46.9%
Needs a lot of support	964	50.9%	44	16.8%
Supported Person Involved?	No.	%	No.	%
Yes	607	33.8%	-	-
No longer	221	12.3%	-	-
No	967	53.9%	-	-
Attitude Towards Alzheimer Society	No.	%	No.	%
Very Likely	1415	78.6%	185	75.5%
Likely	344	19.1%	52	21.2%
Not Likely	42	2.3%	8	3.3%

COVID-19 Impact on Alzheimer Society Care

On March 17, 2020, the Government of Ontario declared a state of emergency in response to COVID-19.¹⁰ Over the coming year many non-essential businesses would be forced to close, and healthcare providers including the Alzheimer Society shifted to virtual programming where appropriate.

Virtual programming: During the pandemic, programs and supports offered by Alzheimer Societies across the province were shifted online or to telephone calls. This included counselling as well as social recreation, education, care partner respite, and others. Of the Alzheimer Society clients who responded to the survey, 65.4% of persons living with dementia and 68.4% of care partners accessed the online and virtual resources during the pandemic. For those who were able to access the online and virtual programs, the vast majority of these respondents indicated they would continue with virtual care, signaling that this type of content was beneficial.

Need for services: During the pandemic, the survey found that 20.6% of persons living with dementia noted an increase in need for Alzheimer Society support programs. The individuals living with dementia who identified as needing “some support” or “a lot of support” were more likely to report this increase in programming needs.

With increased isolation and demand on informal care during the pandemic, some care partners experienced physical and emotional exhaustion, health problems, and feelings of anxiety, depression, and irritability—leading to care partner stress or burnout. The survey found that 29.8% of care partners noted that the stress of COVID-19 and social isolation resulted in an increase in need for services from the Alzheimer Society.

Coping during the pandemic: The shift to offer virtual Alzheimer Society programs became a lifeline for a large number of Society clients. The survey asked if respondents felt that their Alzheimer Society engagement helped them manage social isolation. Forty-four per cent of those living with dementia and 46.4% of care partners felt their engagement in Alzheimer Society programs helped them cope during the pandemic.



44.4% of those living with dementia
and **46.4% of care partners** felt their
engagement in Alzheimer Society programs
helped them cope during the pandemic.

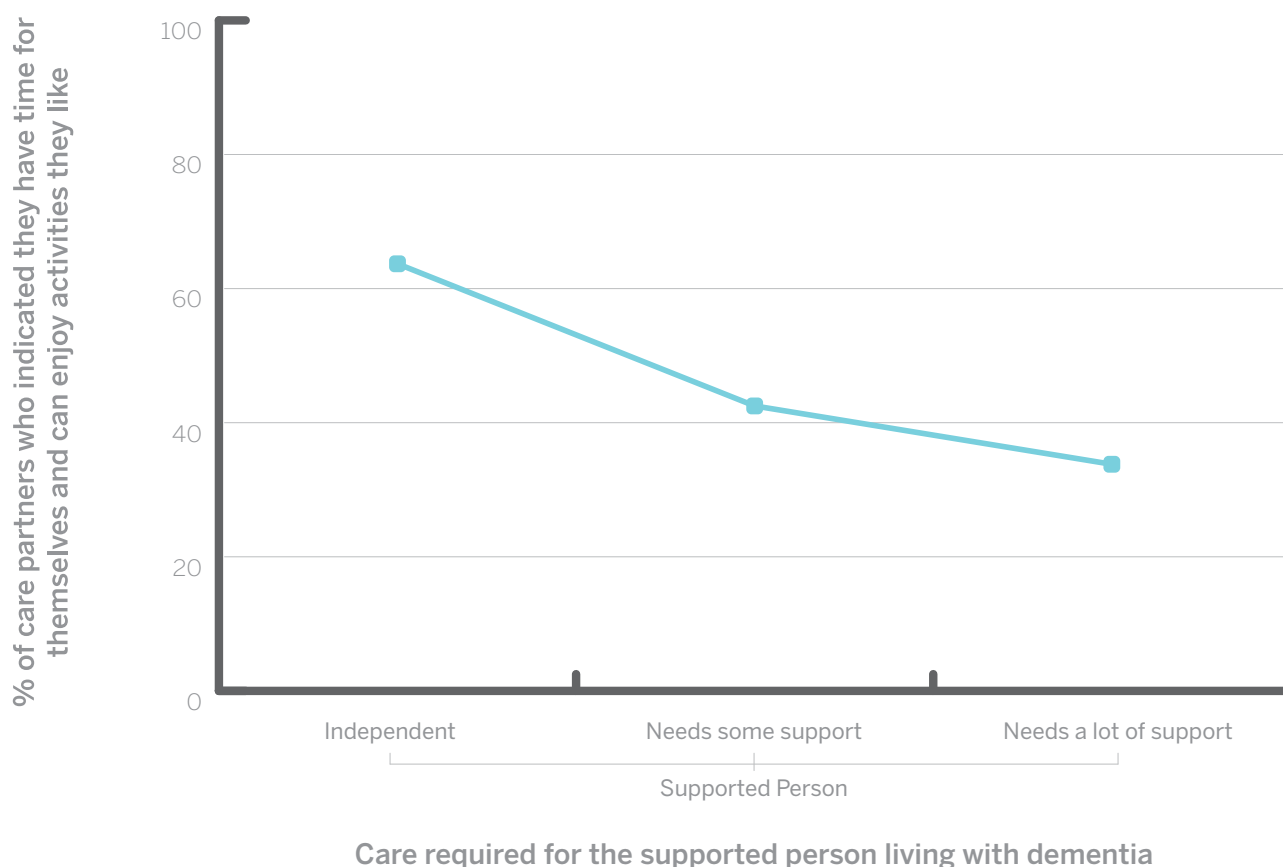
General Overview on Quality of Life

A care partner's role is complicated and can include a number of tasks beyond providing direct care, including transportation to appointments, assistance navigating the healthcare system, emotional and physical support during crises, and help around the home. The role often generates stress that stems from these and other caregiving duties.¹¹

The most significant impact on a care partner's quality of life is time for self-care. The survey asked care partners if they felt they had time for themselves and to enjoy activities they like. While 63.7% of care partners indicated they had time for self-care when the person they supported with dementia was independent, that number decreased to 33.8% when the person they supported needed a lot of support. In general, the quality of life for care partners decreased as the person living with dementia progressed with the condition.

Overall, the survey demonstrated that care partners have a challenging role, and the quality of life of care partners is impacted regardless of the level of support they provide. As care partners play an invaluable role, it is essential that support is available to ensure they can still live well while caring for someone living with dementia. Failing to adequately care for care partners will likely result in decreased health of the care partner.

Care Partner Quality of Life: Time for Self Care

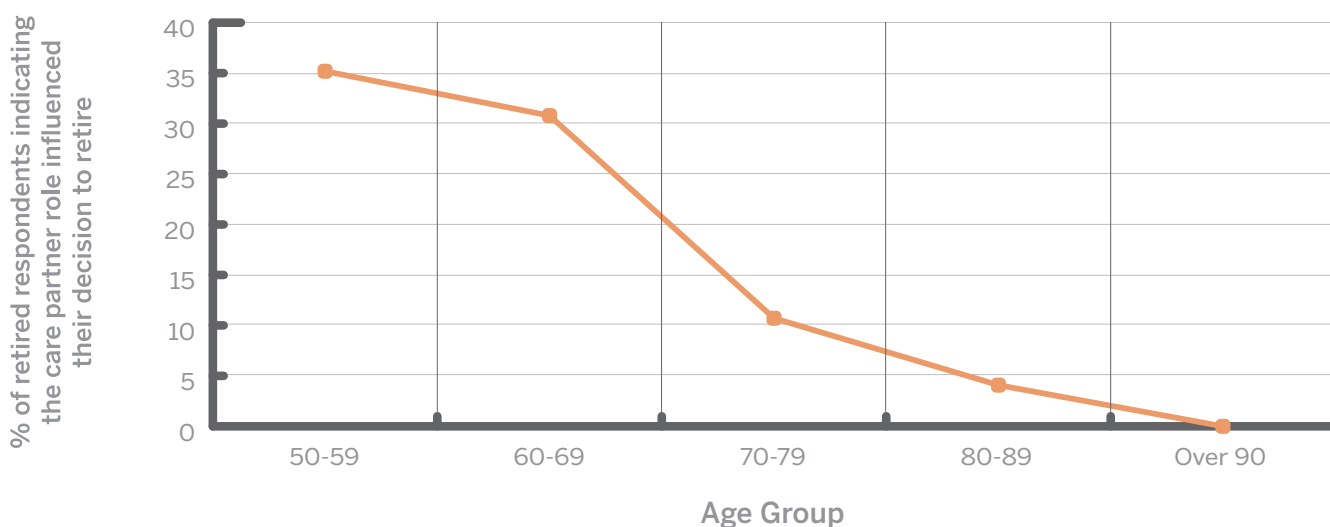


Employment Impact

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 impact on work productivity is affected by a dementia diagnosis, respondents were asked to verify their employment status. Sixty-three per cent of care partners were retired, and 89.8% of those living with dementia identified as retired.

The respondents who identified as retired were asked if their role as care partner, or their dementia symptoms, affected their retirement decision. More than 12% of persons living with dementia and 15.9% of care partners indicated their diagnosis or caregiving duties influenced their decision to retire. This had a dramatically higher impact on younger care partners with approximately one third of retired respondents under the age of 70 reporting their role as care partner impacted their retirement decision.

Impact of Caregiving on Retirement Decisions



My wife was diagnosed with vascular dementia. 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 she continued to decline, I decided to retire in March, which was about a year earlier than planned.

— care partner



Work Productivity

In some cases, care partners or those diagnosed with dementia are still at an age where they remain in the workforce. For respondents who were employed, they were asked if their role as a care partner or their dementia symptoms affected their work.

Close to 60% of employed care partners noted their caregiving duties had negatively impacted their work productivity. On average, they estimated missing 19.6 days of work per year to engage in caregiving responsibilities.

For every working care partner who missed an average of 19.6 days of work per year due to their caregiving role, there was annual loss of \$4,021.92 in productivity.* However, these 19.6 days do not take into account care partners who attend work, but have reduced productivity because of the emotional strain of their caregiving role. This suggests that \$4,021.92 is the base cost of reduced productivity for individual care partners.

Employment Status of Respondents

	Person Living with Dementia		Care Partner	
Employment Type	No.	%	No.	%
I prefer not to answer	4	1.6%	53	2.9%
Unemployed	7	2.8%	59	3.3%
Employed	2	0.9%	369	20.4%
Retired	229	89.8%	1141	62.9%
Sick leave or long-term disability	6	2.4%	39	2.2%
Another	7	2.8%	152	8.4%



For care partners who reported missing work, **an average of 19.6 days of work were missed per year**, resulting in a **loss of \$4,021.92** in productivity.

**Number is based on estimates by the care partner on their days of missed work. See methodology for more information.*

Extended Time at Home

Living well for someone diagnosed with dementia often corresponds to living at home for as long as possible. Surveys of Ontario seniors consistently find that all or nearly all want to continue to live at home as they age.¹² This desire carries benefits for the provincial healthcare system: aging at home is more cost efficient and relieves stress on both hospital and long-term care capacity.



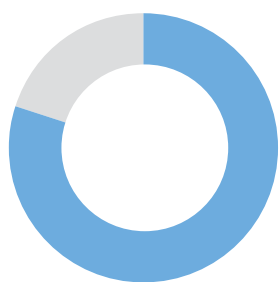
She's at a stage now where I don't think she'd be at home – we wouldn't be living together still – if it hadn't been for our experience with the Alzheimer Society. It's given us a little more time together.

– care partner



The Alzheimer Society provides information and resources to assist care partners and those living with dementia to stay at home longer. Close to 80% of care partners and 76.1% of those living with dementia were able to live or provide care at home longer due to the Alzheimer Society's involvement.

For care partners providing informal care to a person living with dementia in assisted living or long-term care home, 39.8% indicated that Alzheimer Society support delayed their decision to access assisted living or long-term care. These respondents estimated that Alzheimer Society support delayed this decision by 1.38 years, or nearly 500 days. Delaying access to long-term care has a significant impact on the healthcare system: **for care partners who reported a delay in accessing a long-term care bed, the cost savings are \$75,527.***



79.4%

of care
partners

were able to live or provide care at
home longer due to the Alzheimer
Society's involvement



76.1%

of people living
with dementia

For those still at home, 20% of persons living with dementia and 28.4% of care partners noted they would have likely accessed long-term care at the time of taking the survey if it had not been for the Alzheimer Society's support. Rather than entering long-term care, the Alzheimer Society made it possible for care partners to continue providing care at home. An additional \$54,730 is saved each year when a care partner is able to support someone living with dementia at home.

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

**See methodology for more information.*

Distress Intervention

Crisis situations can arise suddenly, when a stressful event—large or small—becomes unmanageable. For people living with dementia, these situations of heightened distress often lead to unnecessary trips to the emergency room.¹³

The Alzheimer Society works with care partners and those living with dementia to prevent crises and prepare for when an emergency occurs. The survey results highlight the success of this intervention—33.6% of care partners agreed that the Alzheimer Society helped them avoid crises.

Care partners who reported avoiding crises estimated that an average of 2.11 acute interventions that likely would have led to the need for hospital care were avoided each year due to Alzheimer Society support.* Preventing a person living with dementia from having to visit the hospital 2.11 times saved the healthcare system \$13,396.39 annually.**



For those whose supported person required a hospital stay, 35.1% of care partners noted their engagement with the Alzheimer Society helped increase their confidence in providing care following hospitalization. This care partner confidence may result in shorter hospital stays or fewer readmittances following an initial discharge from the hospital—all potential benefits of an Alzheimer Society-supported care partner.

**Based on estimates by care partners on their perceived crisis avoidance.*

***See methodology for more information.*



I am able to cope much better. I have literally dropped off my husband at the ER before as I was at the end of my rope. Now, I have skills to communicate with him better and avoid arguments.

— care partner





Care Partner Support

When assessing the value of the Alzheimer Society, the survey identified three ways in which the Society provided support that resulted in savings for Ontario's healthcare system.

1

The first was **support to help those living with dementia in times of distress**.

Care partners who avoided crises reported 2.11 fewer visits to the hospital due to Alzheimer Society support.

2

The second was a **delay in accessing a long-term care bed**. For care partners whose supported person is living in an assisted living or long-term care home, 39.8% indicated that Alzheimer Society support delayed their decision to access assisted living or long-term care by 1.38 years.

3

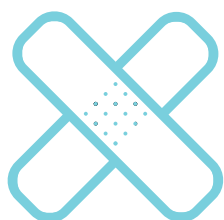
The third was those care partners who were **providing care at home** at the time of the survey. If it had not been for Alzheimer Society support, 28.4% of care partners would have accessed long-term care earlier.

When taking into account acute interventions avoided, delays in accessing long-term care, and the ability to provide care at home, every care partner engaged with his or her local Alzheimer Society resulted in savings of \$16,261.25 for Ontario's healthcare system.* Further savings may be possible with supported care partners; this value is a summary of the three factors described above.

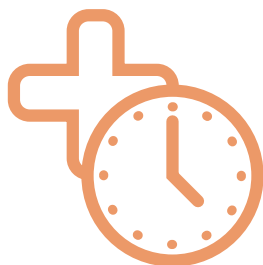
**See page 18 on long-term care funding for more information*

“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.

– care partner”



acute interventions
avoided



delay in accessing
a long-term care bed



providing
care at home

= **\$16,261^{.25}**

in savings for every care partner
supported by an Alzheimer Society*

Care partners served by Ontario
Alzheimer Societies in 2020:

82,089

Resulting in a total
estimated savings of:**

\$1,334,869,751^{.25}

*For the cost savings calculation, see the full Alzheimer Society metrics report at brainscan.ca/alzheimer-report

**Value in 2020 (\$1,334,869,751.25) = Savings for every care partner (\$16,261.25) * Number of care partners served by Ontario Alzheimer Societies (82,089)

Long-Term Care in Ontario

According to a 2019 report from the Ontario Long Term Care Association, 90% of long-term care residents have some form of cognitive impairment and 64% have been diagnosed with dementia.¹⁴

In Ontario, long-term care is regulated and funded by the provincial government. However, publicly funded long-term care homes can either be public or private. As of June 2021, there were 627 homes licensed to operate in Ontario—16% were publicly owned, 57% were owned by private for-profit organizations, and 27% were owned by private not-for-profit organizations.¹⁵

Even though a number of long-term care homes in Ontario are privately owned, the provincial government still provides funding. All personal and nursing care in long-term care homes are funded by the government.

In 2021-2022, the Ontario government is projected to spend \$6.9 billion on long-term care.¹⁶

Impact of the Alzheimer Society on Long-Term Care

Alzheimer Societies in Ontario offer programs and services that help care partners provide assistance for someone living with dementia at home. The survey found that 28.4% of care partners would have accessed long-term care earlier, had it not been for the support of the Alzheimer Society. When accounting for every care partner supported by an Alzheimer Society in Ontario, **this ongoing support at home results in estimated savings of \$890,603,262 annually.***

If it were not for the Alzheimer Societies in Ontario supporting care partners, the healthcare system would need to increase its \$6.9 billion budget allocated to long-term care by \$890+ million per year – covering the number of individuals living with dementia who are currently supported at home.



Had it not been for the support of the Alzheimer Society, **28.4% of care partners** would have **accessed long-term care earlier.**

**For cost calculations, see page 38 of the full Alzheimer Society metrics report that can be downloaded at brainscan.ca/alzheimer-report/*

Methodology

In early 2021, the first Ontario-wide impact survey was distributed to Alzheimer Society clients throughout the province. A number of questions for the impact survey were developed through the Alzheimer Society of Ontario's collaborative work with the Centre for Community Based Research (CCBR).

The cumulative distribution from all 29 Ontario Societies was 12,613 surveys - 10,584 (83.9%) were sent the online survey while 2,029 (16.1%) received a paper version. In total, 1,912 care partners and 272 of those living with dementia completed the survey.

Western's online survey tool, Qualtrics, was used. A paper version of the survey was made available to both those living with dementia and care partners. The survey was also available in French and English. Once the survey closed, 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 for meaningful comparisons. For example, the age group of younger than 30 and 30-49 were pooled to a single "under 50" group to ensure a large enough pool of respondents to extract meaningful data.

New participants were noted as "new" when their engagement duration was less than one year. This one-year cutoff was used as those individuals would not have responded to the previous reporting cycle's survey.

The weighted mean of agreement values were calculated from $[(\text{percent respondents}) * (\text{weight of agreement})]$, where "No" was weighted at -1, "Sort of" at 0, and Yes at +1. This yields an agreement score range from -1 to +1.

Attitude toward the Alzheimer Societies was extracted from the question, "how likely are you to recommend the Alzheimer Society to a family member, friend or colleague dealing with a similar situation?" Those who were very likely to recommend, were considered to have the most positive attitude of their local Alzheimer Society, followed by likely, with unlikely to recommend indicating a negative attitude.

There are three incidences where the return on investment calculations were performed.

- A **hospital visit for acute care** was valued at \$6,349 based on the Canadian Institute of Health Information (CIHI) for 2019-2020¹⁷
- The **provincial contribution toward long-term care beds** was valued at \$54,730/bed per year, based on the 2018 Ontario Budget, LTCH Level-of-Care Per Diem Funding Summary from July 1, 2018¹⁸
- A day of **employment productivity** was valued at \$205.20, based on Statistics Canada's average wage of \$27.36 per hour for an average workday of 7.5 hours in 2018¹⁹

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

Conclusions

Alzheimer Society Impact

Before conducting the survey, Alzheimer Societies in Ontario relied heavily on anecdotal evidence of their impact on care partners and those living with dementia. This Ontario-wide impact survey from BrainsCAN was designed to translate those Alzheimer Society client opinions and experiences into measurable data.

What is the impact of Alzheimer Society programming and services on care partners and those living with dementia in Ontario?

The survey demonstrated the value of Alzheimer Society programs and services with an overwhelmingly positive approval from care partners and those living with dementia. Over 95% of respondents indicated they would recommend Alzheimer Society services to others, with 78% of that group reporting very likely to recommend.

Alzheimer Society programming was also found to be valuable during the pandemic. While COVID-19 required the delivery of in-person programs and services to be shifted online, a large number of care partners and those living with dementia still depended on care and support from their local Alzheimer Society. These programs became a lifeline for some during the pandemic with 44.4% of those living with dementia and 46.4% of care partners reporting that Alzheimer Society programs helped them cope during times of social isolation.

Does Alzheimer Society support have a positive effect on Ontario's healthcare system?

Three factors were determined to save the healthcare system funding when care partners participated in Alzheimer Society programming and services. Acute interventions avoided, delays in accessing long-term care, and the ability to provide care at home resulted in savings of \$16,261.25 for every care partner supported by the Alzheimer Society. In 2020, more than 82,000 care partners were supported by Alzheimer Societies in Ontario, resulting in a total cost saving of \$1,334,869,751.25.

Summary

The first Ontario-wide impact survey demonstrated the value of Alzheimer Society programming and services for care partners and those living with dementia. It also highlighted the important role care partners play in dementia care.

For those living with dementia, their wellbeing often coincides with the ability to live in their homes and participate in their community for as long as possible. Care partners are essential to making this a reality. Ensuring care partners are supported and confident in providing support can ensure those living with dementia are able to live well with the condition. Support by the Alzheimer Society makes this possible.

Acknowledgements

Western's BrainsCAN, the Alzheimer Society Southwest Partners, and the Alzheimer Society of Ontario would like to thank the following for their assistance with the survey and report:

- **Clients of the Alzheimer Societies in Ontario**
- **Alzheimer Societies across Ontario** for contributing and distributing the survey to clients
- **Christina Stergiou-Dayment**, Senior Director, Provincial Programs & Partnerships at the Alzheimer Society of Ontario for leading the project and editing the report
- **Srija Biswas**, Programs Manager, Provincial Programs and Partnerships, Alzheimer Society of Ontario for managing the project and editing the report
- **Kyle Fitzgerald**, Manager, Government Relations and Public Policy at the Alzheimer Society of Ontario for contributing to the project and editing the report
- **Jessica Hogle**, Public Policy Assistant, Alzheimer Society of Ontario for contributing to the project and editing the report
- **Ryan Salewski**, Associate Director, Metrics and Planning at Western University's BrainsCAN for leading the project, analyzing the client survey data and writing the full analysis report
- **Jasmin Gow**, Communications Specialist at Western University's BrainsCAN for contributing to the project and providing survey edits
- **Maggie MacLellan**, Communications Specialist at Western University's BrainsCAN for contributing to the project and writing the summary report
- **Hassam Ansari**, Communications Officer at Western University's BrainsCAN for website development
- **Carol Walters**, CEO of the Alzheimer Society Southwest Partners for leading the project and editing the report
- **Bruce Wray**, Manager, Marketing and Communications, Alzheimer Society Southwest Partners for editing the report

References

¹ Alzheimer's Disease International. **"Dementia statistics"**.

Retrieved from: <https://www.alzint.org/about/dementia-facts-figures/dementia-statistics/>

² Hopkins, R. (2010). Dementia Projections for the Counties, Regional Municipalities, and Census Divisions of Ontario. Geriatric Psychiatry Programme; Clinical / Research Bulletin, Number 16.

³ Centers for Disease Control and Prevention. (2019). **"What Is Dementia?"**.

Retrieved from: <https://www.cdc.gov/aging/dementia/index.html>

⁴ Alzheimer Society of Canada. (2021). **"What is dementia?"**.

Retrieved from: <https://alzheimer.ca/en/Home/About-dementia/What-is-dementia>

⁵ World Health Organization. (2021). **"Dementia: Social and economic impact"**.

Retrieved from: <https://www.who.int/news-room/fact-sheets/detail/dementia>

**Economic cost converted to Canadian dollars*

⁶ Government of Ontario. (2016). **"Developing Ontario's Dementia Strategy: Discussion Paper"**.

Retrieved from: <https://www.ontario.ca/page/developing-ontarios-dementia-strategy-discussion-paper>

⁷ Alzheimer Society of Canada. (2016). **"Prevalence and Monetary Costs of Dementia in Canada"**.

Toronto, Ontario. Retrieved from: https://archive.alzheimer.ca/sites/default/files/files/national/statistics/prevalenceandcostsofdementia_en.pdf

⁸ Statistics Canada. (2013). **"Portrait of caregivers, 2012"**. Retrieved from: <https://www150.statcan.gc.ca/n1/pub/89-652-x/89-652-x2013001-eng.htm>

⁹ Government of Canada. (2019). **"A Dementia Strategy for Canada: Together We Aspire"**.

Retrieved from: <https://www.canada.ca/en/public-health/services/publications/diseases-conditions/dementia-strategy.html>

¹⁰ Government of Ontario. (2021). **"Report on Ontario's Provincial Emergency from March 17, 2020 to July 24, 2020"**.

Retrieved from: <https://www.ontario.ca/document/report-ontarios-provincial-emergency-march-17-2020-july-24-2020>

¹¹ The Change Foundation. (2019). **“Spotlight on Ontario’s Caregivers”**. Retrieved from: https://ontariocaregiver.ca/wp-content/uploads/2019/12/Spotlight-on-ontarios-caregivers-2019_EN.pdf

¹² Home Care Ontario. (2020). **“Home Care Ontario Study”**. Retrieved from: <https://static1.squarespace.com/static/5ed5ba488f3def4cae17ed81/t/5f2c7c5d9d3ca77620440c43/1596750941487/HCO+Release+-+07-08-22+-+FINAL.pdf>

¹³ Canadian Institute for Health Information. **“Seniors with dementia more likely to be hospitalized, stay longer in emergency department”**. Retrieved from: <https://www.cihi.ca/en/dementia-in-canada/dementia-across-the-health-system/dementia-in-hospitals>

¹⁴ Ontario Long Term Care Association. (2019). **“The role of long-term care”**. Retrieved from: <https://www.oltca.com/oltca/OLTCA/LongTermCare/OLTCA/Public/LongTermCare/FactsFigures.aspx?hkey=f0b46620-9012-4b9b-b033-2ba6401334b4>

¹⁵ Canadian Institute for Health Information. (2021). **“Long-term care homes in Canada: How many and who owns them?”** Retrieved from: <https://www.cihi.ca/en/long-term-care-homes-in-canada-how-many-and-who-owns-them>

¹⁶ Financial Accountability Office of Ontario. (May 2021). **“Ministry of Long-Term Care: Spending Plan Review”**. Retrieved from: <https://www.fao-on.org/en/Blog/Publications/2021-ltc-estimates>

¹⁷ Statistics Canada. (2019). **“Wages by occupation, 2018”**. Retrieved from: <https://www150.statcan.gc.ca/t1/tbl1/en/tv.action?pid=1410030701>

¹⁸ Ontario Budget. (2018). **“A Plan for Care and Opportunity”**. Retrieved from: <https://budget.ontario.ca/2018/budget2018-en.pdf>

¹⁹ Canadian Institute for Health Information. (2019). **“Cost of a Standard Hospital Stay”**. Retrieved from: <https://yourhealthsystem.cihi.ca/hsp/inbrief?lang=en#!/indicators/015/cost-of-a-standard-hospital>



Alzheimer Society Impact:

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

brainscan.ca/alzheimer-report/