

Understanding
dementia

2017-2018
IMPACT
REPORT

Alzheimer *Society*
CANADA

Our vision:

A world without Alzheimer's disease and other dementias.

Our mission:

To alleviate the personal and social consequences of Alzheimer's disease and other dementias and to provide research.

Our values:

Summarized by the acronym CARE, our values are **collaboration, accountability, respect and excellence** in everything that we do.

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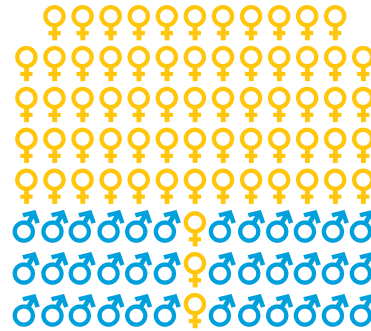
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Understanding the role of the Alzheimer Society of Canada

BY THE NUMBERS

THE URGENCY

	TODAY	2031
Canadians living with dementia	500,000+	937,000
Costs of caring for Canadians with dementia	\$10.4 BILLION	\$16.6 BILLION



Of those living with dementia aged 65 + **65%** are women



\$359

MILLION
Cost to bring a dementia-treating drug from lab to market



1 in 5 Canadians have experience caring for someone living with a form of dementia

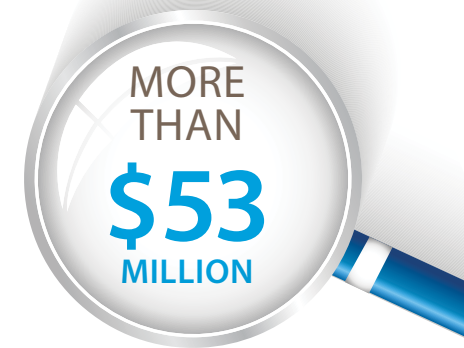


56%

of Canadians are concerned about being affected by Alzheimer's disease

Of greatest concern is their fear of being a burden to others, and of losing their independence and the inability to recognize family and friends

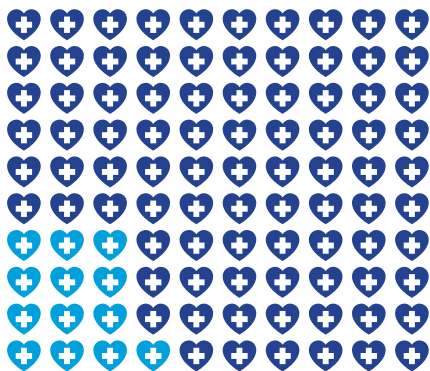
THE PROGRESS



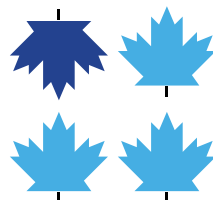
invested to date in research through the Alzheimer Society Research Program

25,000

Canadians participated in the 2017 Walk for Alzheimer's to support those affected by dementia



87% of caregivers wish that more people understood the realities of caring for someone with dementia



1 in 4 Canadians admit they would feel ashamed or embarrassed if they had dementia



Pauline Tardif, CEO

We must first seek to understand

My mother is living with late-stage vascular dementia.

As one of her caregivers, I am well-acquainted with the services the Alzheimer Society can provide to those living with dementia. I am also painfully aware of the current limitations of our country's supports and resources when it comes to meeting the needs of this rapidly growing community.

I also understand the impact of stigma. **Stigma is what caused my parents to wait a long time before telling our family about my mother's dementia diagnosis.** And as we learned this year in our research, they were not alone. We learned that 50 per cent of Canadians would not want others to know if they had Alzheimer's disease. We learned that one in five Canadians admit that if they thought they had dementia they would avoid seeking help for

as long as possible, perhaps to avoid embarrassment and stigma.

These results confirm our belief that **stigma is one of the biggest barriers for people with dementia to live fully with dignity and respect.** The findings underscore the work we must still do to end stigma once and for all. There is no shame in having dementia. We can't let negative perceptions stand in the way of people with dementia seeking help and support. Life without discrimination is a right for anyone affected by this disease.

Our three-year awareness campaign, "Yes. I live with dementia. Let me help you understand," tackles the issue of stigma head-on through the stories of Canadians who are living with Alzheimer's disease and other dementias (read more on page 8). We are grateful to our ambassadors for their candour and bravery in sharing their experiences to help us all understand.

Alzheimer's disease and other dementias are gaining national profile in other ways, too. As the development of the **national dementia strategy** moves forward, we are collaborating with like-minded partners like never before (read more on page 14). The leading-edge research you are helping to support through the **Alzheimer Society Research Program** is edging us closer every day to finding more effective treatments and the cure for Alzheimer's disease, as well as new and innovative ways of improving the care of and quality of life of people with dementia. More Canadians are raising awareness and money through our national Walk for Alzheimer's each year. And we're expanding community programs like **Minds in Motion**® (read more on page 15), with multiple benefits for participants with dementia and for those who interact with and care for them.

It is essential that we continue to build on this momentum. **As the number of Canadians living with Alzheimer's disease and other dementias grows exponentially, our support of dementia research needs to grow even faster.** Many researchers are optimistic that we are close to breakthroughs in finding the answers we need to fight and cure this disease. Now more than ever before is the time for us to focus and ensure that they are well-supported.

Ensuring that support means building more dementia-inclusive communities. And that begins with understanding. I invite you to visit ilivewithdementia.ca to learn more about the experiences of your fellow Canadians. Let's work together to increase everyone's understanding of dementia.



Understanding people living with dementia

Those who have been diagnosed with dementia often struggle with misconceptions about the disease.

Dementia is not a natural part of aging even though age is the biggest risk factor: After 65, your risk for dementia doubles every five years.

But it is not just a disease of the elderly—you could be diagnosed in your 50s, 40s or even 30s. →

Faye Forbes:
**Building understanding through
active social connections**

Shocked by her diagnosis of Alzheimer's disease at age 57, Reverend Faye Forbes says that the right medication and a positive outlook have helped her to not only manage her symptoms, but also to set a positive example for everyone she interacts with. Eight years after her diagnosis, she has achieved her goal of becoming an ordained minister, participates in numerous events and educational forums to help increase understanding of dementia, and is a director of the board of the Alzheimer Society of Canada. Faye also shared her experience as part of this year's awareness campaign, including appearing in several videos outlining typical symptoms of dementia and strategies for dealing with them. "Alzheimer's is not the end of life," says Faye. "I'm still the same person as I was before. I have the same feelings and outlook. I can still think for myself but just can't always express my thoughts as I used to."

Reverend
Faye Forbes



Dementia refers to a group of conditions that affect the brain and cause problems with memory, thinking, speaking or performing familiar tasks. But Alzheimer's and other dementias don't fundamentally change—or define—the people who are living with them. And with the right help and support, people living with dementia can continue to do the things they love and remain active in their communities.

People living with dementia tell us, “**Nothing about us, without us.**” They have the right to be actively involved in the work of organizations, like the Alzheimer Society, that represent their interests. It's up to us to learn how to accommodate their needs to make their engagement possible—and meaningful.

Canadian Dementia Priority Setting Partnership study

In 2017, researchers at the Toronto Rehabilitation Institute, University Health Network, Dr. Jennifer Bethell and Dr. Katherine McGilton surveyed more than 1,200 Canadians living with dementia, as well as their friends, family, caregivers and health-care providers. They identified their **top 10 dementia research priorities**, which will help to

inform researchers and research funding organizations as well as the Government of Canada's national dementia strategy.


The initiative, known as the **Canadian Dementia Priority Setting Partnership study**, was funded by the Alzheimer Society Research Program as part of our commitment to the Canadian Consortium on Neurodegeneration in Aging (read more about both initiatives on page 11).

The top priority identified in the study came as a bit of a surprise to researchers: It was understanding the stigmas associated with dementia, their impact, and strategies for reducing them.

“Yes. I Live With Dementia”: Our three-year nationwide awareness campaign

With stigma identified as our top research priority, the Alzheimer Society of Canada surveyed more than 1,500 Canadians in November 2017 to learn more about their attitudes and beliefs when it comes to Alzheimer's disease and other dementias. Using the survey results, we developed a three-year multi-channel awareness campaign with the goal of **increasing understanding** of the realities and experiences of Canadians who are affected by dementia.

The cornerstone of the campaign was the **powerful, first-person stories** of 37 ambassadors from across Canada whose lives have been touched by Alzheimer's and other dementias in some way, each with the headline: “**Yes. I live with dementia. Let me help you understand.**” A bilingual digital toolkit was provided to all provincial Societies containing key messages, customizable print materials, radio scripts, social media posts and images, and tips on how to run the campaign locally.

Alzheimer Societies ran the campaign as part of national Alzheimer's Awareness Month in January 2018. The results were astounding, with national radio, television and newspaper coverage, viral social media activity, nearly 25,000 visitors to ilivewithdementia.ca, and a 2,397 per cent increase in media reach year over year. 

Roger Marple:
Sharing his experience
to educate others

Since he was diagnosed with young onset Alzheimer's disease in 2015, Roger Marple has become a vocal advocate for others, working to dispel myths about the disease and reduce the stigma surrounding dementia.

As a participant in the Canadian Dementia Priority Setting Partnership study, he helped to identify the top 10 dementia research priorities for Canadian researchers and research funding organizations. As one of eight members of the Alzheimer Society of Canada Advisory Group, all living with dementia, he contributed to the development of a resource manual to help organizations foster the meaningful engagement of those living with the disease. He and other members of the Advisory Group have also led training sessions to help Alzheimer Society staff become even better partners for people with dementia. And perhaps most important, he has shared his experience through our awareness campaign. "Dementia does not discriminate and that includes age," says Roger. "When you meet someone with dementia, clear your mind of any preconceived perceptions you may have and see the person for who they are—in the here and now."



Roger Marple

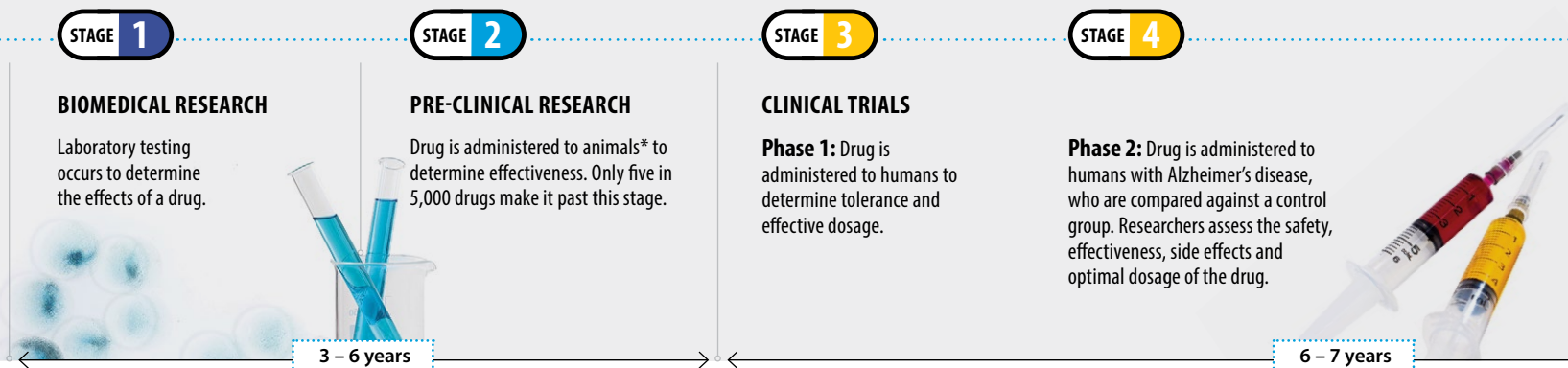
Understanding the role of research

Research is getting us closer every day to finding the cause and the cure for Alzheimer's disease and other dementias, as well as new and effective approaches to improving care and quality of life for those living with dementia.

Finding a treatment will benefit all Canadians by improving the lives of all who are touched by dementia, reducing the growing burden on our health care system, and helping to create a better future for the next generation.

We're proud to support some of Canada's brightest minds in this vital work. →

How drugs are approved in Canada for the treatment of Alzheimer's disease



The Alzheimer Society Research Program (ASRP)

Celebrating 30 years, our flagship national peer-reviewed program awarded \$3.4 million to 24 researchers working on a range of biomedical and quality-of-life research projects. We are grateful to Alzheimer Societies and donors across the country for funding the ASRP.



Canadian Consortium for Neurodegeneration in Aging (CCNA)

The largest effort to understand dementia in Canada is the Canadian Consortium for Neurodegeneration in Aging (CCNA). More than 350 clinicians and researchers throughout Canada have come together to form the CCNA and are accelerating progress in the research of Alzheimer's disease and other age-related neurodegenerative diseases, including Vascular dementia, Frontotemporal dementia, and Lewy body dementia.

As a founding CCNA partner, the Alzheimer Society of Canada has committed \$4.05 million over five years (2014-2019) to these efforts and is proud to have supported many of the researchers leading key projects within the CCNA through the Alzheimer Society Research Program. Achievements to date include:

- Establishment of 20 teams across Canada doing cutting-edge research in the areas of prevention, treatment and quality of life
- Publication of research findings in more than 100 scientific journals
- Creation of a national patient cohort of more than 2,000 Canadians for research purposes
- Ongoing knowledge transfer to public and policy makers through a dedicated program
- Collaboration with other federal initiatives, including the Centre for Aging & Brain Health Innovation (CABHI), the Canadian Longitudinal Study on Aging (CLSA), and AGE-WELL

On average it takes **12 years and \$359 million** to bring a drug from the research lab to a person with dementia.

STAGE 5

CLINICAL TRIALS – CONTINUED

Phase 3: Phase 3 Clinical Trial application is submitted to the Therapeutic Products Directorate (TPD) of Health Canada. This phase includes additional people with Alzheimer's disease who also have other conditions for which they are taking additional medications. Drug effectiveness, side effects, use and ideal dose are considered among a broader population.

STAGE 6

NEW DRUG SUBMISSION

Drug is submitted to the Therapeutic Products Directorate of Health Canada for risk/benefits assessment. If its benefits outweigh risks for target users, the Health Products and Food Branch of Health Canada will approve the drug.



STAGE 7

ONGOING MONITORING

Health Canada continues to monitor drug's effectiveness and side effects after approval.

0.5 – 2 years

Research highlights



Dr. Anne Almey



Dr. Gillian Einstein

Investigating the connection between estrogen and dementia

As women tend to live longer than men, they also have a higher risk of developing dementia. However, age may not tell the whole story behind women's higher susceptibility to the disease.

Supervised by Dr. Gillian Einstein (a distant cousin of famed scientist Albert Einstein), Wilfred and Joyce Posluns Chair in Women's Brain Health and Aging at the University of Toronto, and Dr. Natasha Rajah, Director of The Brain Imaging Centre at the Douglas Institute, and Associate Professor, Department of Psychiatry at McGill University, post-doctoral fellow Dr. Anne Almey is using her ASRP funding to study the role that estrogens play in both cognitive and brain health in women. She will compare a specific population of women with low levels of circulating estrogen with a control group of women with normal levels of circulating estrogens.

Dr. Almey hopes to clarify the role that estrogens play in cognitive and neurobiological functioning in women, and perhaps contribute to treatments to slow the progression or prevent the development of Alzheimer's disease in women.



Dr. Simon Duchesne

Detecting dementia years before symptoms begin

There is growing evidence to suggest that certain changes can be detected in the brain years—even decades—before symptoms of dementia begin to appear. Supported by an ASRP biomedical grant, Dr. Simon Duchesne, Associate Professor in the Radiology Department at Université Laval, and who is also the Chair of the ASRP Biomedical Panel, is using magnetic resonance imaging (MRI) to study the brains of individuals with dementia and those without the disease.

Dr. Duchesne's goal is to identify the disease early, thereby maximizing the treatment window—and therefore the effectiveness—of both lifestyle and drug approaches to combat Alzheimer's and other dementias.



Dr. Debra Sheets

Understanding the power of music to improve quality of life

One of the frequent side effects of Alzheimer's, for those with the disease and for their caregivers, is social isolation. The benefits of music and the arts for people living with dementia are well-known, and anecdotal evidence has shown choirs to be particularly promising. Choirs provide their members with a sense of connection, improved mood and self-esteem, reduced stress, and an opportunity to express their voices and learn more about each other.

Using a quality of life grant from the ASRP, Dr. Debra Sheets, Associate Professor in the School of Nursing at the University of Victoria, is studying the benefits of an intergenerational choir for people with dementia. Voices in Motion is an intergenerational choir that brings together people with Alzheimer's disease, caregivers and high school students from the community in Victoria, B.C. The goal is to use the study's findings to create a toolkit of best practices that can be used by other organizations who are interested in starting a community choir for people with dementia.

Understanding the role of partners

Our corporate and community partners are helping to expand our reach and impact in amazing ways.

They contribute their expertise and energy through ongoing programs and annual events to make a difference for people

in their own communities and across Canada whose lives are touched by Alzheimer's disease. →



David Hearn

Minds in Motion®

Research shows that a healthy lifestyle can not only help to reduce our risk of dementia and other chronic diseases, but may also improve quality of life, slow the progression of the disease and improve capacity to manage some of the challenges of the disease.

That's the thinking behind the Alzheimer Society's Minds in Motion® program, a physical activity and cognitive stimulation program for people in the early to middle stages of dementia and their caregivers.

First developed by the Alzheimer Society of BC in 2009, the program, which is currently available in 16 locations, has expanded to 12 additional pilot sites across Canada with more in the planning stages—thanks to support from the Canadian Centre for Aging & Brain Health Innovation's Industry Innovation and Partnership Program. Throughout the eight-week program, participants are led through a series of simple exercises that focus on flexibility, strength and balance, with some fun and challenging activities thrown in such as Zumba or dancing. Brain games, trivia, visual arts, creative storytelling and a host of other activities make up the cognitive portion of the program.



Participants in a Minds in Motion class

For people with dementia, there are multiple benefits of Minds in Motion: improved balance and mobility, sharpened mental functioning, increased confidence and a sense of social inclusion. In fact, many participants choose to seek out additional exercise and community programs beyond their weekly Minds in Motion class.

For caregivers, it's an opportunity to focus on their own health and well-being, all while having fun with the person they care for. And at one site, 90 per cent of staff and volunteers at the

recreation centre hosting the program reported an increase in their knowledge and understanding of older adults and/or dementia.

"There is one gentleman who is quite far into his Alzheimer's and we wondered if maybe the group was too much for him," says the daughter of a Minds in Motion participant. "But then things in his brain started turning on. His caregiver told us he was doing things he hadn't been able to do before. Another lady told me it's helped her memory. It's helped her spirit. That is something a doctor can't prescribe."



Canadians participating in the Walk for Alzheimer's to raise funds to help those with Alzheimer's and other dementias

RBC Wealth Management, Estate & Trust Services and planned giving

More than 90 per cent of the planned gifts we receive at the Alzheimer Society of Canada are from wills and bequests. Our partnership with RBC Wealth Management's Estate & Trust Services team began in 2016 and focuses on helping us ensure that our online resources for Canadians who are interested in making a planned gift to the Alzheimer Society in this way are clear and supportive. Our RBC partners have also helped us educate our community members about the opportunities for legacy and planned giving to the Society. Visit the **Gift in your Will** page at alzheimer.ca to explore our resources, which include blog posts and videos with legacy donors as well as estate and trust experts on why and how to incorporate a planned gift into your will.



Wealth Management
Estate & Trust Services

The David Hearn Foundation

After losing two close family members to Alzheimer's disease, PGA Tour golfer David Hearn and his wife, Heather, were driven to help others who are affected by the disease. Founded in 2015, The David Hearn Foundation's central focus is to support the Alzheimer Society of Canada in increasing awareness, improving care for those in need and enhancing quality of life for those affected by Alzheimer's disease, while also empowering Canadians to act and create positive change.

In July 2017, The Foundation hosted the sixth annual David Hearn Foundation Golf Classic, raising more than \$130,000 to support the work of the Alzheimer Society of Canada and the Alzheimer Society of Brant, Haldimand Norfolk, Hamilton Halton. To date, the Hearn Classic has raised more than \$500,000 to help Canadians living with Alzheimer's disease and the people who care for them.



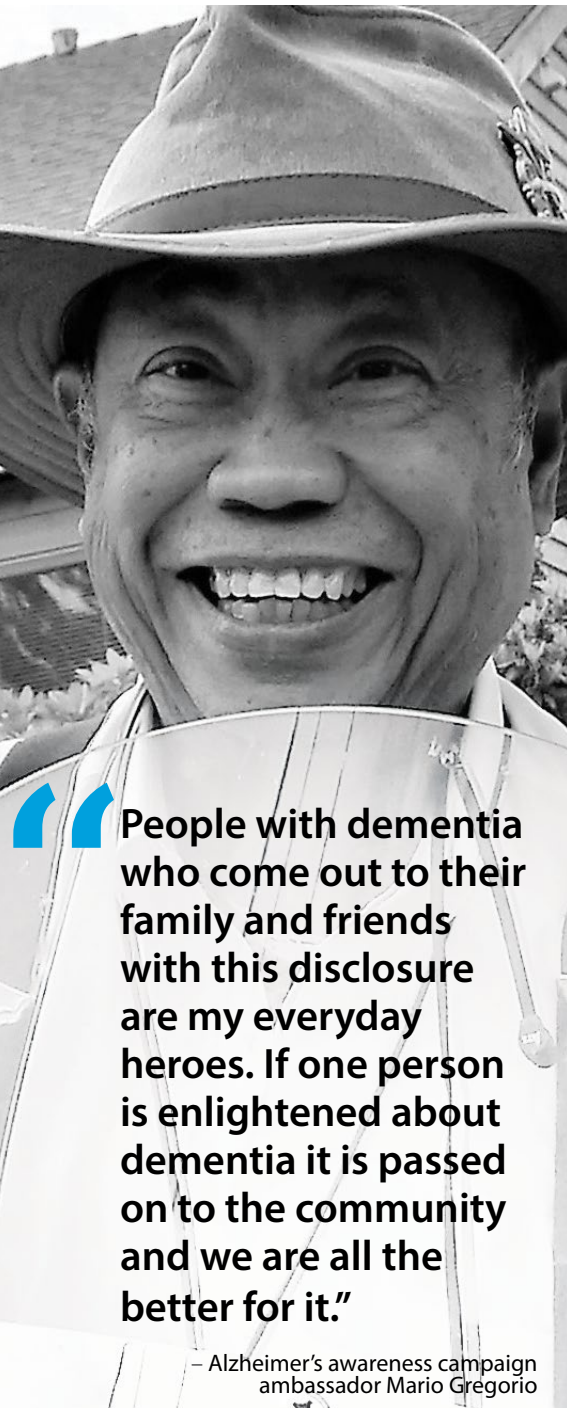
Extendicare

In July 2017, Extendicare Assist, the management and consulting division of Extendicare Inc., hosted its sixth annual Charity Golf Classic in Ottawa to benefit the Alzheimer Society of Canada. The tournament has raised more than \$600,000 to date—\$127,000 in 2017. Extendicare's contributions have been used to create a Relational Caring Learning Series to improve the quality of care and life for Canadians living with Alzheimer's disease and other dementias in long-term care homes.

Relational caring, or person-centred care, is a model of care based on relationships of respect, trust, compassion and empathy between those who work in long-term care, residents with dementia, their caregivers and families. The Relational Caring Learning Series is an important component of our ongoing work to drive a much-needed culture change toward person-centred care.

Learn more about our culture change initiative at: alzheimer.ca/culturechange





“People with dementia who come out to their family and friends with this disclosure are my everyday heroes. If one person is enlightened about dementia it is passed on to the community and we are all the better for it.”

– Alzheimer's awareness campaign ambassador Mario Gregorio

Walk for Alzheimer's

The national Walk for Alzheimer's (newly branded as the Investors Group Walk for Alzheimer's in April 2018), is Canada's biggest fundraiser for Alzheimer's disease and other dementias. Each year, enthusiastic walkers come together for a common goal: to raise vital funds for local Alzheimer Society programs and services, which will help individuals and families living with Alzheimer's disease and other forms of dementia. More than 25,000 participants in more than 250 walks raised over \$4.9 million in communities across Canada in 2017. To learn more and sign up for the Investors Group Walk for Alzheimer's in your community, visit walkforalzheimers.ca.



Coffee Break®

In 2017, 2,000 Coffee Break events were held in communities across Canada, raising \$600,000—money that directly benefits programs and services offered by local Alzheimer Societies. Our longest-running fundraiser, Coffee Break has grown from a grassroots initiative to a community celebration of friends, families and neighbours who gather together at public venues to donate funds in exchange of a cup of coffee and show their support for those living with or caring for someone with dementia. Thank you to Melitta, our in-kind sponsor, for making this year's event a success. Find out more about Coffee Break at alzheimer.ca/coffeebreak.



Understanding the role of government

On June 22, 2017, Canada committed to a national dementia strategy. The passing of *An Act respecting a national strategy for Alzheimer's disease and other dementias* means the Government of Canada will address the overwhelming scale, impact and cost of dementia.

Our national dementia strategy will become our single most powerful tool to transform and elevate Canada's dementia care.

The experiences of countries with national dementia strategies show that coordinated, targeted efforts at the national level improve results for all aspects of dementia care and research.

The strategy itself is expected to be delivered in early 2019. Policy makers, people living with dementia, caregivers, and stakeholders from across the country are working together to offer feedback and suggestions for this precedent-setting national dementia strategy. The Alzheimer Society of Canada is proud to contribute to the development of the strategy and will continue to be a vocal advocate for all Canadians affected by dementia.

Understanding the role of donors

**Thank!
you!**

Your generous support is helping us to find a cure and identify potential new disease-modifying therapies for Alzheimer's, understand the

different forms of dementia, and enhance quality of life, care and safety for all those who are affected by dementia. →



Caroline Wight: Giving to support other caregivers

Caroline Wight and her husband, Laurence, worked side-by-side as real estate agents for many years of their 48-year marriage. But when Laurence was diagnosed with Lewy body dementia and Caroline's mother with Alzheimer's disease, Caroline suddenly found herself in the full-time role of caregiver.

Supporting both her husband and her mother with home-care workers while trying to maintain her career was overwhelming and isolating. "As a caregiver to two loved ones, I knew that if I crumbled, the whole castle was going to fall," says Caroline. "I wish I had known the Alzheimer Society could have helped all of us, but I didn't. I thought we had to cope by ourselves."

Caroline didn't discover the Alzheimer Society until both her husband and mother had passed away, eight years later. "Because of my own lonely experience, I always encourage caregivers to contact the Alzheimer Society. And I'm so impressed with their work that I've included the Alzheimer Society in my will," says Caroline. "No one should have to face dementia alone."

**Laurence and
Caroline Wight**

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Statement of Financial Position

March 31	2018	2017
Assets		
Current		
Cash	\$ 3,403,713	\$ 2,694,493
Short-term investments (Note 3a)	311,220	1,983,698
Accounts receivable (Note 2)	4,889,966	4,734,537
Prepaid expenses	49,054	44,309
	8,653,953	9,457,037
Long-term investments (Note 3b)	8,376,726	7,967,363
Restricted long-term investments (Note 3b)	1,201,907	1,151,729
Property and equipment (Note 4)	41,103	43,725
	\$ 18,273,689	\$ 18,619,854
Liabilities and Fund Balances		
Current		
Accounts payable and accrued liabilities (Note 5)	\$ 5,472,745	\$ 6,286,226
Deferred revenue (Note 6)	2,310,150	2,185,808
Research grants payable (Note 7)	2,100,229	2,114,304
	9,883,124	10,586,338
Deferred revenue (Note 6)	2,169,462	2,216,018
Research grants payable (Note 7)	543,407	623,528
	12,595,993	13,425,884
Fund balances		
Endowment fund	972,936	1,027,261
Invested in property and equipment	41,103	43,725
Internally restricted operating reserve	2,431,648	2,431,648
Internally restricted research fund	1,646,926	1,568,328
Unrestricted fund	585,083	123,008
	5,677,696	5,193,970
	\$ 18,273,689	\$ 18,619,854

On behalf of the Board:

 Director

 Director

Understanding the role of the Alzheimer Society of Canada

The Alzheimer Society is Canada's leading nationwide health charity for people living with Alzheimer's disease and other dementias.

Alzheimer Societies across the country offer programs and services, research funding, public education and awareness campaigns, and advocacy for people impacted by all forms of dementia, including Alzheimer's disease.

We rely on individual and corporate donors, communities and health-care partners to help us carry out our vital work. →

A wealth of supportive resources

We have developed and continually add to a wide range of up-to-date, evidence-based resources—all searchable online at alzheimer.ca—for those living with Alzheimer's disease and other dementias, and for health-care professionals.

Our goal is to help people dealing with dementia make informed decisions and live as well as possible, from diagnosis to end of life.

In fact, in this year alone we distributed nearly **1.5 million resources** to our provincial and local Alzheimer Society partners who deliver direct services.



Our **Moving to long-term care** series, for example, offers advice on everything from planning to handling the transition to long-term care for all family members, including printable checklists for evaluating long-term care homes and packing for the move.

Our **Meaningful visits tips** help you foster closer bonds when you visit someone living with dementia.

And our advice on **end-of-life** and **palliative care** can help you support someone in the later stages of the disease.

Learn more

Visit alzheimer.ca for hundreds of helpful resources and to locate the Alzheimer Society in your community

Take the pledge

I pledge to:

BE VOCAL if I hear a joke or other conversations that create stigma.

BE PATIENT if I encounter someone with dementia.

BE SUPPORTIVE to people living with dementia and their families.

Get involved

Volunteer with your local Alzheimer Society

Join in your local Walk for Alzheimer's

Participate in your local Coffee Break® event

Give generously

Visit alzheimer.ca to give online, or phone 1-800-616-8816 to speak with us

Alzheimer Society of Canada

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Phone: 416.488.8772
Toll Free: 1.800.616.8816
Email: info@alzheimer.ca
Website: alzheimer.ca

Alzheimer *Society*
C A N A D A