Finding the way forward

2018-2019 IMPACT REPORT



1.1 million Canadians are affected by dementia.

25,000 new cases of dementia are diagnosed every year •

Over 500,000 Canadians live with dementia today

937,000 Canadians will have dementia in less than 12 years•

Each of these dots = 25,000 Canadians:



- = will have dementia in less than 12 years
- = affected by dementia
- = new cases of dementia per year
 - = general population

Addressing dementia as a nation

More than 1 million Canadians have some sort of connection to dementia, and we count ourselves among them.

In addition to our lived experience, we have been privileged to learn about the experiences of others who are living with the numerous challenges of Alzheimer's disease and other dementias-in growing numbers.

We need to address dementia as a nation, and the June 2019 release of Canada's first-ever national dementia strategy, A Dementia Strategy for Canada: Together We Aspire, is a significant step in the right direction. The strategy follows years of advocacy on behalf of the Alzheimer Society of Canada and the input of key stakeholders, including people with lived experience, partners in the dementia and health care communities, and members of the Minister of Health's Ministerial Advisory Board on Dementia.

The vision for the national dementia strategy is "a Canada in which all people living with dementia and caregivers are valued and supported, quality of life is optimized, and dementia is prevented, well understood, and effectively treated." The strategy's three national objectives are to prevent dementia, advance therapies and find a cure, and improve the quality of life of people living with dementia and of their caregivers.

The federal government has committed \$20 million over five years for community-based projects that support the challenges of living with dementia, and \$50 million over five years for initiatives promoting risk reduction, prevention and combatting stigma. Implementing the broad and significant objectives of the national dementia strategy will require further and sustainable investment if we are to achieve its vision.

Another important achievement in the past year was the launch of the Canadian Charter of Rights for People with Dementia—another first. The Charter was created by the Alzheimer Society of Canada's Advisory Group of People with Dementia to empower Canadians with dementia to self-advocate while also ensuring that those who support them understand and protect their rights. We encourage you to learn about the seven rights outlined in the Charter on page 7 and at alzheimer.ca/Charter, and to share them with those you care about.

In the pages that follow, we highlight some of the amazing work of our nation's talented researchers funded by the Alzheimer Society Research Program and supported by the incredible generosity of our donors. We also profile Canadians who are living with Alzheimer's disease and other dementias whose experiences help us all understand.

At the Alzheimer Society of Canada, we will continue to shine a light on the many ways that dementia impacts our daily lives, and to listen to the stories of people living with this disease.

It is essential that every one of us continues to speak up—for ourselves and for those we love. $\langle 0 \rangle$

Pauline Tardif, CEO

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Ian Rea, Chair, Board of Directors

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Pauline Tardif

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Our vision

A world without Alzheimer's disease and other dementias.



Alex and Donna on their wedding day.

Our mission

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

Our values

Collaboration. Accountability. Respect. Excellence.

Dear Alzheimer Society:

My wife, Donna, and I met when we were just teenagers—she was 18, I was 16. Despite our youth, we understood early on that we had a deep connection. It was an amazing thing, really, and still is.

In 2009, Donna was diagnosed with young onset Alzheimer's disease. She was 47. I remember sitting beside her in the chair in the doctor's office. I looked at her, and she looked at me, and I said, "We'll get through this together." And we have, with the love and support of our family, neighbours, community and church.

We've also had tremendous support from our local Alzheimer Society, whose staff and volunteers have been there for us almost since the day Donna was diagnosed. Whenever I have a question or concern or just need to talk, I know I can turn to them. We've received individual support and participated in group sessions that help me be a better, more patient caregiver. I encourage others to seek out the support they need from the Alzheimer Society, and to donate what they can to help fund those programs for other families.

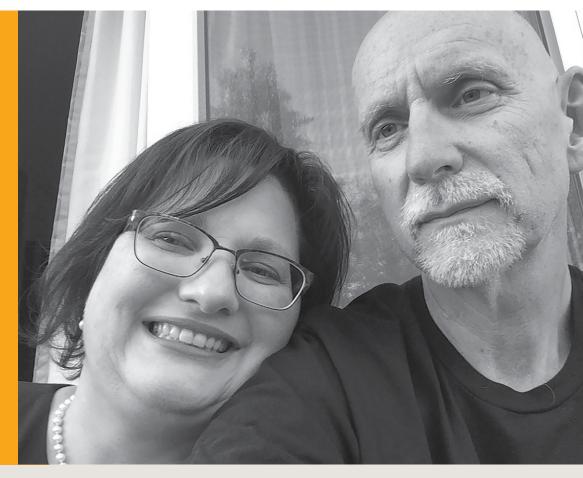
Ten years later, the love of my life is in the final stages of Alzheimer's disease. I never pictured our life together like this, but I'm grateful that we're not going through it alone.

Alex

Understanding people living with dementia

"Know that when we signed on to be partners, we signed on to support each other. My role does not change just because of a diagnosis. We have cared for each other for years and plan to continue to do this."

> ---Robin, whose husband, Keith, was diagnosed with young onset dementia at age 57 (read their stories at ilivewithdementia.ca).



"Yes. I live with dementia. Let me help you understand."

Canadians with dementia led year two of our anti-stigma campaign in 2019 by sharing their personal stories of living with the disease. Thousands of Canadians visited the website ilivewithdementia.ca to be inspired by their day-to-day achievements, learn about the struggles as well as the triumphs of fellow Canadians and broaden their understanding about Alzheimer's disease and other dementias.

56% of Canadians are concerned about being affected by Alzheimer's disease.

First-ever Canadian Charter of Rights for People with Dementia

As difficult as it is to receive a diagnosis of dementia, people with dementia tell us that it can be even more devastating to experience the stigma of this disease on a daily basis. To protect their human rights and give themselves a voice, the Alzheimer Society of Canada's Advisory Group of People with Dementia created the firstever Canadian Charter of Rights for People with Dementia in 2018.

The Charter empowers people with dementia to understand and advocate for their rights. It is also meant to help policy makers, health-care professionals and organizations pause and reflect on how they currently interact with people with dementia and consider how they can ensure the rights of people with dementia whom they support.

Help share and spread the word: alzheimer.ca/Charter.

"I don't hide that I have Alzheimer's, but it's my choice when and how to talk about it. Our Charter of Rights is a reminder for me, and those who interact with me, that I am still here, and I am still a person."

- Marilyn, one of nine members of the Alzheimer Society of Canada's Advisory Group that created the Canadian Charter of Rights for People with Dementia, mother, stepmother, grandmother, greatgrandmother, retiree, animal lover and daily walker.

CANADIAN CHARTER OF RIGHTS FOR PEOPLE WITH DEMENTIA

As a person with dementia, the following rights are especially important to me. I have the right:

To be free from discrimination of any kind.	To benefit from all of Canada's civic and legal rights.	To participate in developing and implementing policies that affect my life.
To access support so that I can live as independently as possible and be as engaged as possible in my community. This helps me: • Meet my physical, cognitive, social, and spiritual needs; • Get involved in community and civic opportunities; and	5 To get the information and support I need to participate as fully as possible in decisions that affect me, including care decisions from the point of diagnosis to palliative and end-of-life care.	 To expect that professionals involved in my care are: Trained in both dementia and human rights; Held accountable for protecting my human rights, including my right to get the support and information I need to make decisions that are right for me; Treating me with respect and dignity; and Offering me equal access to appropriate
 Access opportunities for lifelong learning. 		• Othering the equal access to appropriate treatment options as I develop health conditions other than my dementia.

To access effective complaint and appeal procedures when my rights are not protected or respected.

Understanding the role of research

Research moves us forward. Your support will get us closer to life-altering treatments, better care and a cure.



The Alzheimer Society Research Program

In 2019, our national peer-reviewed Research Program awarded \$2.1 million to 20 researchers across the country working on projects to find the cause and the cure, as well as effective treatments, for Alzheimer's disease and other dementias.

Our Program is one of the few in Canada that focuses solely on dementia research. Fifty per cent of our funds are directly invested in producing advances in science, from improving diagnosis to finding cures, while 50 per cent go towards enhancing practices and care in order to ensure Canadians affected by dementia live as best possible in their homes and their communities.

During the 2018-19 period, we celebrated the completion of Phase I of our partnership with the Canadian Consortium for Neurodegeneration in Aging (CCNA). To date, we have invested close to \$3 million in CCNA-led research.

We are grateful to donors for their generous support and to the fundraising efforts of our provincial Alzheimer Society partners. \$59.8M invested to date

Funding allocation

50 % to cause 50 % to % to care

Partners in the Canadian Consortium for Neurodegeneration in Aging (CCNA)

The Alzheimer Society of Canada is a founding partner and the lead funder of the CCNA through the Alzheimer Society Research Program. Established in 2014, the Canadian Consortium for Neurodegeneration in Aging is a nationwide collaborative platform that includes more than 350 clinicians and researchers who are investigating Alzheimer's disease and other age-related neurodegenerative diseases, with a focus on prevention, treatment and quality of life.

During Phase I, we supported these important areas of the CCNA's work to help accelerate the development of new dementia treatments and improve care:

- Building capacity through training;
- Knowledge translation and exchange activities; and
- Prioritizing dementia research to improve quality of life.

Research highlights

Dementia Dogs: Supporting people with dementia

DID YOU KNOW?

People with lived experience are included in all aspects of the Alzheimer Society Research **Program**—from the volunteers who participate in studies through our Research Portal (at alzheimer.ca/ResearchPortal) to the Citizen Reviewers who provide their unique insights on policy and funding decisions. Our Citizen Reviewers are also keynote speakers and frequent presenters at research conferences and meetings, helping to ensure that their lived experience informs the decisions and actions of the research and dementia care communities.

Dr. Claude Vincent is passionate about improving care and support for people living with dementia. She is leading the first Canadian study that looks at whether people with dementia and their caregivers can benefit from the full-time support of a dog. Dr. Vincent's research team is assessing the impact of both regular companion dogs and certified assistance dogs—known as "Dementia Dogs." These dogs are trained to provide cues and companionship and can help encourage physical activity, improve wayfinding, and enhance well-being and connection. Previous studies have shown that support animals can help improve quality of life for people living with other disabilities, and now Dr. Vincent and her team hope to demonstrate this same positive impact for people living with dementia. The results of her study will help families living with dementia understand the potential benefits of having a companion animal in their home, while also informing the development of new in-home support programs.

"Funding options are very limited for this type of research, but it is so important. The Alzheimer Society Research Program may be the best way to develop new approaches to improve the quality of life of people living with dementia and their caregivers." —Dr. Claude Vincent

Dr. Claude Vincent Occupational Therapist and Professor in the Department of Rehabilitation, Faculty of Medicine at Laval University

2 The role of lifestyle-related risk factors

3 The "exercise hormone" and memory formation

Dr. Gordon Francis wants to get to the root of

what causes dementia. That's why he is investigating the connection between dementia and cerebral amyloid angiopathy (CAA)—a neurological condition where a protein called beta-amyloid builds up on the walls of the arteries in the brain. CAA increases a person's risk of both stroke and dementia. Dr. Francis and his team believe that when arteries in the brain are damaged by "lifestyle" risk factors, including high blood pressure, smoking, diabetes and high cholesterol—as well as through the normal aging process—their ability to clear the sticky beta-amyloid proteins is reduced.

Proving this connection would mean that reducing lifestylerelated risk factors could be a form of early treatment to prevent or reduce the development of CAA and the dementias that can result from it.

DID YOU KNOW? Having a stroke more than doubles your risk of developing dementia.

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Dr. Gordon Francis Endocrinologist and Professor of Medicine in the

Centre for Heart Lung Innovation and Department of Medicine at St. Paul's Hospital, University of British Columbia

Dr. Fernanda De Felice wants to find ways to protect the brain from the devastating effects

of Alzheimer's disease. Dr. De Felice is studying a protein called irisin, sometimes referred to as "the exercise hormone" because it is released by muscles during physical activity. She believes that irisin could help preserve memory for people living with Alzheimer's disease and other dementias. In previous research, her team found that people with Alzheimer's have less irisin in the brain—and when that irisin is depleted, new memories aren't formed. If the decrease of irisin in the brain can be counteracted through medication or exercise, this may be a way to keep brain cells and synapses healthy and lead to new treatments to combat dementia.

DID YOU KNOW? Regular physical exercise can reduce your risk of developing Alzheimer's disease by up to 50 per cent. Exercise can also slow further deterioration in people who have already started to develop cognitive problems.

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Dr. Fernanda De Felice Associate Professor in the Centre for Neuroscience Studies and the Department of Biomedical and Molecular Sciences at Queen's University

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Exploring breakthroughs in dementia research



Building a creative and supportive research culture is key in delivering scientific advances in dementia. It's one of the reasons why we provide funding for researchers throughout the continuum of their research activities, from initial explorations to more established theories. Dr. Andrea Leblanc has received support from the Alzheimer Society Research Program since 1995. Early in her research, Leblanc suspected that amyloid deposits—which are found in abnormally large amounts in the brains of those with Alzheimer's disease—were a consequence of the disease rather than the cause, as many others hypothesized.

Over 20 years later, Leblanc's search for alternative causes of neurodegeneration has identified a link between caspase enzymes in the brain that cause inflammation, and the breakdown and death of neurons—a hallmark of Alzheimer's disease and other dementias. Even more promising: Dr. Leblanc's lab has had success using an existing drug (originally developed to treat inflammatory diseases) to reverse cognitive impairment and inflammation and inhibit amyloid deposits in mice. The next step is to test the drug in humans.

"Independent of whether one believes amyloid is the cause, neuronal degeneration, defined by the inability of neurons to perform normally due to their altered structure, needs to be stopped and that pathology reversed," says Dr. Leblanc, who hopes to see the drug move into the clinical trial phase in the near future. Because the drug has already been proven safe for humans, this could happen more quickly than with a brand-new drug.

DID YOU KNOW? Several students in Dr. Leblanc's research team are also currently funded by the Alzheimer Society Research Program and are investigating the role of caspases in Alzheimer's disease.

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Dr. Andrea Leblanc

Senior Investigator at the Lady Davis Institute at Montreal's Jewish General Hospital and Professor of Neurology and Neurosurgery at McGill University



RESEARCH PROJECTS FUNDED IN 2019

1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 < PROJECTS



Adrianna with her grandfather Eugene.

Dear Alzheimer Society:

I'm an 18-year-old girl from Ottawa, Ontario. I have sent you this cheque for \$3,500 that I would like to go toward Alzheimer's research. I have also attached a list of the people who contributed to this donation.

In January of this year I lost one of the most important people in my life. His name was Eugene and he was my grandfather. He was diagnosed with Alzheimer's disease 12 years ago. He was only 65 at the time. I can faintly remember the early symptoms, the forgetfulness and slight confusion, but he was still a happy and healthy man. Things started to get more emotionally difficult when he began to forget each of us ... I can never truly tell you the pain I felt when he looked at me with that blank stare. He didn't know me anymore; it was as if I was erased.

The last two years of his life were the toughest. He lost his ability to dress and feed himself, he became easily agitated, and he barely spoke a word to anyone ... I understand that I'm not the only person in this world who had to go through this, and we are only one family out of millions who have or are currently going through the same thing.

I will always hate Alzheimer's, from the day my grandfather got it to the day he died and until the day someone finds the cure. I hope that this donation will help get us to that point soon because unfortunately it wasn't soon enough for him.

Adrianna

Estate of Kenneth Snowdon

Estate of Laura Louise Wickett

Estate of Linda Deborah Johnson

Estate of Margaret Cunningham

Estate of Margaret Ruth Thompson

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Thank you! Your generous support is helping us to find a cure and identify potential new treatments for Alzheimer's disease, understand the different forms of dementia, and enhance quality of life, care and support for all those who are affected by dementia.

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65% of those diagnosed with dementia over the age of 65 are women.

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Why I give:

Jane Soper Kennedy and the Warren Y. Soper Charitable Trust

"My father established a trust before he passed away with the goal of supporting organizations involved in health and medical research. He was a successful, communityfocused businessman and sportsman. My late brother was a pharmaceutical researcher and I had an extensive career as an occupational therapist in hospitals, long-term care and the community (Veterans Affairs Canada).

My first experience with Alzheimer's disease was in my work. As my career progressed, I saw more and more patients with dementia, and I saw the devastating effect it had on entire families. When my aunt Anne, my father's sister, was diagnosed with Alzheimer's, it touched our family directly. We all admired her sharp mind and her love of learning, and it was difficult to watch her decline. I also lost a long-time friend to young onset dementia. Alzheimer's disease is like a living death.

I am hopeful that a cure for Alzheimer's disease will be found soon. In my work, I saw the benefits of Aricept [a drug used to treat symptoms of Alzheimer's disease] in some of my patients in its early days. And over the



Jane Soper Kennedy with her father, Warren Y. Soper.

past 15 to 20 years the stigma around this disease has been reduced due to education and improved community support for those living with the disease, as well as their caregivers.

I don't think there's a family in North America that has not been touched by Alzheimer's. I am honoured and privileged to continue our family legacy of giving back by supporting the ongoing and important research to find preventative measures, effective treatments, and a cure for this disease. That is why we continue to support the Alzheimer Society of Canada."

Jane Soper Kennedy is a trustee of the Warren Y. Soper Charitable Trust, which has generously supported the Alzheimer Society Research Program since 2014.



Understanding the role of partners

Making a lasting impact through a planned gift

Did you know that leaving money to charity in your will is a highly effective way to reduce taxes on your estate? Through our partnership with RBC Wealth Management, Estate & Trust Services, we've developed helpful online resources for Canadians who wish to make a legacy gift to the Alzheimer Society of Canada. Visit alzheimer.ca/ GiftInYourWill to learn more and to read inspiring stories from legacy donors on why they give.



Wealth Management Estate & Trust Services

Why I give: Linda Janes

"This disease has taken the lives of so many of my family members. At each funeral, I've requested donations to Alzheimer's research in lieu of flowers.

I also recommend a planned gift to everyone. I am 77 years old, and I have hope that I'll see treatments improve in my lifetime. And I feel good knowing that my money will make an impact long after I'm gone as well.

I don't have children, so a Will gift was very meaningful to me. Even if I had children to think of, I would still make sure a portion of my estate went to my favourite charity. The Alzheimer Society is doing their very best to advance research into this disease. They're doing better and better all the time, and we all need to be a part of it."

0------0

Linda Janes has generously included the Alzheimer Society in her Will.

" I walk because my beloved wife, Agatha, had dementia. She was a beautiful woman who always strived to create awareness of the disease in the community and to show people, in her words, that 'I'm still me.' Walking for the Alzheimer Society was her contribution to raise the profile of the work that they do, as well as raise funds to support research so that someday a cure can be found."

- Paul, participant in the 2018 IG Wealth Management Walk for Alzheimer's



IG Wealth Management Walk for Alzheimer's

IG Wealth Management is the generous national partner of Canada's biggest fundraising event for Alzheimer's disease and other dementias, with IG Wealth Management employees across the country stepping up in a range of ways to understand, raise funds and rally around Canadians living with dementia. The 2018 IG Wealth Management Walk for Alzheimer's attracted close to 30,000 participants in more than 300 communities across Canada. Their efforts raised a record \$5 million to fund the increasing demand for local Alzheimer Society programs that make life better for those affected by dementia.

Learn more about the IG Wealth Management Walk for Alzheimer's in your community, visit walkforalzheimers.ca.

CORPORATE INFORMATION

Our Board of Directors

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Alzheimer Society of Canada/Société Alzheimer du Canada Statement of Revenue and Expenses

For the year ended March 31	2019 2018
Revenue Support from the public Individual giving and direct marketing Bequests Corporate giving and foundation giving	\$ 9,831,927 \$ 9,101,946 1,987,587 1,444,847 1,575,174 1,177,280
Total support from the public	13,394,688 11,724,073
Partner charities Investment and other income	6,845,741 6,781,400 1,039,469 762,519
Total revenue	21,279,898 19,267,992
Expenses Programs Services Research Partner charities	2,664,381 2,356,198 3,828,926 3,814,712 12,918,873 11,182,574
Total program expenses	19,412,180 17,353,484
Support Fundraising Administration	847,200 699,683 688,544 718,966
Total support expenses	1,535,744 1,418,649
Total expenses	20,947,924 18,772,133
Excess of revenue over expenses before unrealized losses on investments	331,974 495,859
Unrealized losses on investments	(97,743) (12,233)
Excess of revenue over expenses	\$ 234,231 \$ 483,626

Complete audited financial statements are available at alzheimer.ca/en/Home/About-us/Annual-report/Financial-statements

Understanding the role of the Alzheimer Society of Canada

The Alzheimer Society is Canada's leading nationwide health charity supporting people living with all forms of dementia, including Alzheimer's disease, as well as their caregivers and their families.

We rely on individual and corporate donors, communities and healthcare partners to help us deliver on our mission.

Active in communities across Canada, the Society offers programs and support services, fundraises to advance research, advocates for policy change, and increases public awareness.

Learn more

Society in your

community

Visit alzheimer.ca for

helpful resources and

to locate the Alzheimer

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 IG Wealth Management Walk for Alzheimer's

Give generously

Visit alzheimer.ca/Donate to give online, or phone 416-488-8772 to speak with us about your goals

Alzheimer Society of Canada

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



Charitable registration number: 11878 4925 RR0001