

# HELP FOR TODAY HOPE FOR TOMORROW

ANNUAL REPORT 22/23

# **LEADING WITH VALUES**

Collaboration, Accountability, Respect, Excellence; are values that are seen in the day-to-day efforts of team members and volunteers. These values are also found in the overarching governance, vision, and leadership of the board in support of our mission.

This past year, we refreshed our strategic plan placing our focus on justice, equity, diversity, and inclusion. Our programs and services are accessible and serve the diverse needs of the Waterloo Wellington community.

Strong themes of collaboration shine in the work we do; through engaged teamwork, active involvement with Ontario Health Teams, community tables, collaborative projects, and public education, we believe in the power of cooperative efforts.

Our Continuous Quality Improvement (CQI) process provides the lens for accountability. Through reporting, dashboards and debriefs, we apply best practices to our business practices finances, social work, volunteer engagement, governance and more.

These values position the Alzheimer Society of Waterloo Wellington well for the

final steps to accreditation in the spring of 2024. We look forward to receiving the endorsement of The Canadian Centre for Accreditation (CCA). As we review and assess our current practices, we are reminded of the exceptional frameworks we have in place and welcome a path of continuous improvement.

Care, compassion, and commitment are the concrete steps to delivering on our mission and vision. ASWW is a sustainable and responsive leader in the field of dementia offering specialized services to all persons along the dementia journey.

As we celebrate our accomplishments this past year, we thank you for walking with us. As we look to the future, we know that we are stronger together. Join us in our efforts to support individuals living with dementia and their care partners. Together we can help them to live their best day.



Kim Cusimano
President
Alzheimer Society
Waterloo Wellington

#### **OUR VISION**

Be a sustainable and responsive leader in the field of dementia, offering specialized services to all persons along the dementia journey

# **OUR STRATEGIC PLAN AT A GLANCE**

We know that there is an expanding need for services and supports for people living with dementia. Clients and care partners are challenged to maintain connections to family, friends, and other supports. Our growing and aging population has an increasing number of diagnoses and higher need for support. And our services don't always reach members of diverse groups in our communities.

#### **Our Beneficiaries**

The impact we want to deliver for our beneficiaries

Responsively meet the needs of isolated individuals living with dementia

Engage and serve individuals from diverse, under-served populations in our region

#### **Our Business Model**

The finance and operations we need in place to achieve this

Maximize service capacity, utilizing volunteers, new partnerships, fund development and community support Successfully complete and achieve accreditation to enhance quality, safety, and risk management culture within the organization

Enhance awareness and participation with ASWW through a fulsome communications and engagement strategy

#### Our People

The human capabilities and culture that will underpin it all

Develop an internal culture and practice of agility, resilience, and responsiveness

# POWER OF PARTNERSHIP

## Michelle Martin, Executive Director Responds to Care Partners

"When I received my diagnosis, I was devastated and thought this was the end. Through a lot of hard work with the Alzheimer Society, I now feel a sense of purpose. My life is meaningful, just different."

We feel so privileged to be able to support people with education, social work support and therapeutic recreational programming, and looking back we have had a wonderful year. Our client satisfaction survey shows that clients appreciate personalized



support. Personal connections make a real difference. Often clients do not realize the range of services available to them. Engaging with clientele keeps our programs and services relevant.

New partnerships were formed to improve Diversity Equity and Inclusion (DEI) so that all people have access to support services. Please take a moment to read about our partnership with Guelph Wellington Immigrant Services. We have also begun work with integrated primary care teams, which means better support and improved access to care for more people.

The goal of accreditation in our strategic plan is well underway. We are implementing a Continuous Quality Improvement (CQI) plan to provide top-quality and responsive services to people living with dementia, their care partners, chosen family and community members. It is through this continuous quality improvement lens that we are the most responsive to our client's needs.

We continue to rely on support from

donors and grant organizations to raise 60% of our budget each year. We are so appreciative of your support. Without the ongoing support of our donors people living with dementia would not receive the care they need to cope with their diagnosis. This client sums up why your support is so important.



"Thank you for helping me get my relationship back. Now that I know how to communicate differently... I feel like I have my husband back."



We are so excited about the new partnerships that have been formed over this past year. These partnerships will ensure that people with dementia receive excellent care. It is an absolute pleasure to inspire people living with dementia to "Live Their Best Day"



Michelle Martin, Executive Director Alzheimer Society Waterloo Wellington

# A STEADY HAND MAKES A DIFFERENCE

Colleen Martin shares how you can find resilience with someone living with dementia

Hearing the phrase, "You might want to consider putting your spouse on a wait list for a care home," is difficult. The weight of this choice is tangible, "It takes my breath away," confided a care partner, "In my heart, I know where this is going, but I want to push it all back."

Caring for someone living with dementia requires a strength of spirit. In this battle of emotions, a care partner said, "the services we received from the social worker were a pillar of strength. The social worker was to guide and a steady hand."

Difficult decisions tend to be affected by emotions. While ASWW staff are "not with me 24 hours a day, ... the information you give me is with me 24 hours a day, and that is what is so helpful. Your compassionate embrace helped keep me focused on making good decisions."

Colleen, an ASWW social worker, says, "It's not just about tending to the practicalities; it's about caring for the hearts of those who care for their loved ones. One-on-one counselling empowers them to navigate new complexities of life with renewed strength."

There is profound upheaval with a diagnosis. Family roles shift, and relationship dynamics can become strained. A dedicated counsellor helped me "focus on my love for my partner and realize I am resilient."







**1981** Care Partners served 646 people living with dementia enrolled in our programs

1310 new referrals. averaging 5.4 new referrals per day

147 Public Education **Sessions Hosted** 

**748** new Care Partners connected to the Alzheimer Society 84 new people living with dementia connected

**1074** total First Link Care Navigation cases

914 First Link interactions and visits

#### Leadership Team 2022-2023

Michelle Martin – Executive Director Gail Roth – Director of Programs and Services Lawrence Lutgendorff – Director of Fund Development Jill Ross - Finance and Executive Coordinator

#### Board Team 2022-2023

Kim Cusimano – President Lisa Deguire – Vice President Uzzam Riaz – Treasurer Cheryl Sarnavka – Secretary Rennie Brudnjak – Past President Jesse Dugard – Director David Bernstein – Director Catherine Jones – Director Len Carter – Director Ian Kaufman – Director Janis Randall Simpson – Director Paul Kerr - Director

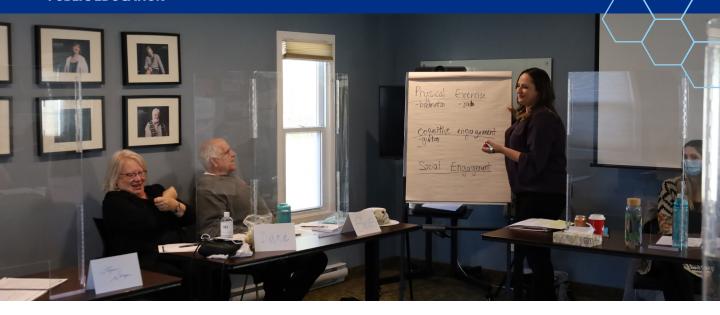
#### Staff 2022-2023

Social Worker - BSW, RSW Colleen Martin, Social Worker - MSW, RSW Yara Janzen, Social Worker - MSW, RSW Patricia Ferrari, First Link Coordinator Kayla Haas, Intergenerational Community Programs Coordinator Gisèle Hauser, Navigatrice des services de soins, Premier Lien/ First Link Care Navigator - MSW, RSW Janine Wilson, Public Education Coordinator Samantha Schultz, First Link Coordinator Rachel Estok, Social Worker - MSW, RSW Robin Smart, Public Education Coordinator Jordan Brazier, Community Programs Coordinator Kim Davidson, Minds in Motion ® Coordinator Sarah Jones, Minds in Motion ® Coordinator Mikayla Girdler, Minds in Motion ® Coordinator Tom Connelly – Volunteer and Events Coordinator Carolyn Vanderzwaag, Fund Development Administration Coordinator Patsy Cerqueira, Receptionist Pete Morey, Virtual Program and Communications Coordinator

Kaitlin Alcock, Social Worker, First Link - MSW, RSW

Jeanetta Grawbarger, First Link Care Navigator/

#### **PUBLIC EDUCATION**



## IN THE COMMUNITY

#### **Public Education Matters**

Public education is at the heart of the Alzheimer Society of Waterloo Wellington and at the heart of building a dementia-friendly community. The Evergreen Seniors Centre partnership in Guelph stands as a testament. Through cost-free and registration-free programs, this collaboration doesn't just raise Alzheimer's awareness but forges connections that uplift our community and break down barriers - empowering a compassionate and informed society.

With doors open to all, this initiative cultivates an inclusive space for learning, reflecting the Society's values. These talks are created for everyone - we often see friends and neighbours of people living with dementia learning and sharing.

A diagnosis of dementia can be isolating; these public classes showcase how diverse individuals come together, emphasizing the significance of raising awareness for dementia, unity, and understanding.

"Public education is the heart of our mission at the Alzheimer Society of Waterloo Wellington, and our partnership with the Evergreen Centre in Guelph, brings people together and empowers a compassionate and informed community."

~ Robin Smart, Public Education Coordinator

# **BUILDING STRONGER ALLIANCES**

## How Sparking a Memory Often Sparks Friendships too

During the pandemic, when we were looking to rekindle our dementia-friendly community, the Alzheimer Society Waterloo Wellington introduced the Spark Phone Program. Picture this: a dedicated volunteer connecting one-on-one with individuals living with dementia through meaningful phone conversations. Three years later, it's become more than just a chat—it's connects us.

"Every call is like sharing stories with a friend," a participant shares.

From captivating trivia to heartwarming reminiscences, the Spark Program transcends distance to create moments of joy. Volunteers pour their hearts into each call, fostering bonds that brighten days.

"I feel like someone cares," an appreciative member reflects.

These conversations ripple with empathy, designed to uplift spirits and kindle connections. We're crafting a community of compassion with every call, one conversation at a time.





- "It is so important to have programs for people living with dementia. The calls are easy for my husband to manage on his own and this gives me a little break."
  - Care partner, on behalf of person living with dementia



#### **OUR YEAR IN PHOTOS**



# **ENRICHING LIVES**

## **Exploring the Profound Impact of In-Person Programs**

As the Minds in Motion Coordinator, I'm humbled by this program's profound impact on lives. Over the last year, shifting to in-person programs, we've cultivated connections and a tapestry of understanding and shared experiences. "Minds in Motion has transformed my journey with dementia into one of hope and vitality," one participant shares.

The camaraderie within our community fostered through gentle exercises, interactive games, and heartfelt conversations, weaves a safety net of support. Witnessing care partners and those living with dementia thriving side by side is inspiring beyond words. MiM doesn't merely focus on the condition; it nurtures the well-being of every participant.

"In MiM, I've found not just escape but a space to flourish," another cherished

member reflects.

Our journey together is a testament to the power of connection, compassion, and camaraderie. Through Minds in Motion, it's a privilege to offer a space for hope and growth.





52 sessions ran virtually and in-person this year, with 8 weeks per session.



494 total participants in Minds in Motion in 2022-2023

# **CONNECTING OUR COMMUNITY**

## Reducing Language Barriers for Dementia Education

"I didn't know what was wrong with my father", said Eun Yung a newcomer to Canada. "He is not the same person anymore." "Limited English Proficiency" is a scholarly term for a problem with a big impact in Waterloo and Wellington. People with low proficiency in the English language experience significant barriers to getting help for loved ones with dementia.

"We quickly realized that the Alzheimer Society Waterloo Wellington (ASWW) were not the experts in engaging newcomers, minority groups or individuals with a culturally diverse backgrounds," said Michelle Martin, Executive Director at

ASWW. The Alzheimer Society was already an active partner with Guelph Wellington Immigrant Services (GWIS) however;" we needed to make our efforts more intentional and focused."

Diversity, Equity, and Inclusion are so

important to us that they are a key pillar in ASWW's Strategic Plan, "Engage and serve individuals from diverse, underserved populations, including newcomer, LGBTQ+, and racialized communities in our region." Studies indicate that older immigrants are 70% more likely to have dementia and there is a growing call for more dementia support for immigrant families.

With the support of the United Way Guelph Wellington, ASWW and GWIS are co-delivering on a dementia training initiative that includes translating and co-delivering dementia education in

key languages. To date, the collaboration has produced "Overview of Dementia" training in three languages: Chinese, Tigrinya and Vietnamese.

Michelle Martin emphasises that, "This culturally sensitive approach to service delivery not only supports people living with dementia in their language of choice but also provides a safe and inclusive introduction to other ASWW supports and services. This approach will reduce barriers now

and well into the future."



#### **FUND DEVELOPMENT**



# **BRIGHT FUTURE**

#### Your Impact in Action

Your donations make a profound impact. Donors like you provide hope for the future. It is through the support of donors that over 16,500 people across this region know that they do not walk alone.

Rob found the support he needed to juggle care giving, work, and household responsibilities when his wife Kathleen's was diagnosed with early-onset dementia. Your support makes the connection possible, allowing Rob to reduce his stress and enhance his wife's quality of life.

Regular support groups are now a part of George's routine. A retired veteran with Alzheimer's, George is one of 494 people who found companionship and solace. His daughter shared how these gatherings brought back moments of joy and connection in his life.

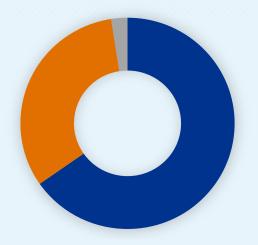
2712 people were connected to an outreach or educational workshop. When Margaret's father was diagnosed with Alzheimer's, she felt overwhelmed and uninformed about the disease. Your contributions facilitated a workshop where

she gained valuable knowledge. As a result, Margaret can provide better care and understand her father's needs with compassion.

#### **Impact Beyond Numbers**

Your commitment to ASWW goes way beyond the monetary contribution. By becoming a donor, you join a community that offers connection and hope to people living with Dementia. Your trust in this cause provides innovative services, ensuring no family faces this challenging journey alone.

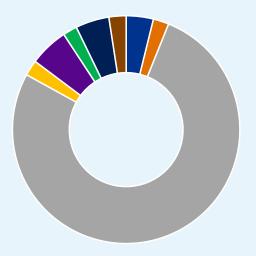
Thank you for your unwavering support and belief in the Alzheimer Society of Waterloo Wellington. You make a real and lasting difference by simply caring enough to give to support people affected by dementia. Your generosity fuels the determination to continue the fight against dementia. Thank you for being a catalyst for change and a beacon of light for those in need.



Revenue	2023
• Fundraising and Grants	\$ 1,171,642
(65%) • Government Funding (LHIN)	\$ 578,957
(32%) ● Interest (2%)	\$ 43,947

**Total REVENUE** 

\$ 1,794,546



Expenses	2023
<ul><li>Salary</li></ul>	\$ 1,395,503
Pro. Dev., Travel,	\$ 40,373
Conferences	
<ul><li>Programs</li></ul>	\$100,395
<ul><li>Fundraising</li></ul>	\$ 36,702
<ul><li>Rent, Utilities and</li></ul>	\$ 86,700
Maintenance	
<ul><li>Office and Capital</li></ul>	\$ 70,184
Expenses	
Insurance, Bank and	\$ 40,399
Professional Fees	
<ul><li>Loss on Investment</li></ul>	\$ 44,258
Total EXPENSES	\$ 1,814,515

# HOPE HAS A NEW FOOTHOLD

#### Monumental Strides for Alzheimer's Research

monumental stride in Alzheimer's disease treatment has arrived, with the Alzheimer Society of Ontario celebrating the full approval of lecanemab (Legembi) by the US FDA. This watershed moment not only signifies the world's first full approvál of an Alzheimer's treatment but also heralds renewed optimism and progress in therapeutic and diagnostic research.

"Today, hope emerges from a place that once felt powerless," Cathy Barrick, CEO of the Alzheimer Society of Ontario, exclaims. "While we've embraced lifestyle choices to reduce Alzheimer's risk, the approval of safe and effective treatments offers newfound possibilities—allowing families and healthcare providers to navigate Alzheimer's more effectively and even slow its progression."

This endorsement follows Legembi's accelerated approval earlier this year, affirming its potential to alter Alzheimer's trajectory in its early stages.

The treatment's submission to Health Canada in May 2023 is a beacon of optimism for Canadians.

However, challenges loom. The urgency for early detection and diagnosis is evident,

as all available treatments, including Legembi, require administration during the early phases of Alzheimer's. Alarming research from the University of Southern California underscores the need for readiness in Ontario, as the introduction of disease-modifying therapies could lead to diagnosis wait times of up to seven and a half vears.

"We've long anticipated this moment in Ontario, and readiness is paramount," Ms. Barrick emphasizes. "With many families affected by dementia, the demand for quality care is clear."

Legembi's introduction, while promising, brings inherent risks. Those considering Alzheimer's treatment should consult their healthcare providers. Amid uncertainties, one undeniable truth shines through hope has found a new foothold, inspiring progress and compassion in the fight against Alzheimer's.





## Ontario isn't ready.

For the first time ever, a treatment for Alzheimer's disease—not just its underlying symptoms—has been submitted for approval to Health Canada. Lecanemab (Leqembi) is already approved for use in the United States. Within the next two years, it is entirely possible that Ontario will be tasked with getting Canada's first-ever approved treatment for Alzheimer's disease to thousands of recipients.

#### And we're not ready.

To be clear this drug is not perfect, and will likely only be prescribed to a small fraction of Ontarians living with Alzheimer's disease. It will not be for everyone, and comes with potentially serious side effects. But it is the first, and as we have seen with other chronic diseases the first approved treatment shows that breakthroughs are possible, leading to a fresh influx of research interest and clinical studies.

This first drug will lead to more. Future treatments will be safer, cheaper, more effective, and able to help more people. How we prepare for this first treatment will set the stage for how we implement future therapies, so it is crucial we get this right.

Last year the Alzheimer Society of Ontario released research showing that, if a treatment for Alzheimer's disease is approved for use in Canada, Ontario is poorly positioned to deploy it. Ontario's lack of preparedness will cost the province nearly \$4 billion in avoidable hospital and long-term care admissions for people living with dementia whose cognitive decline could have been slowed had they had timely access to a treatment.

# Ontarians are watching. We have no time to lose.

The main bottleneck will be diagnosis. Today, it takes between 12-18 months on average to secure a diagnosis of Alzheimer's disease in Ontario. With the introduction of a disease-modifying therapy, this wait time will skyrocket to seven and a half years—by which time treatments that need to start during the earliest stages of Alzheimer's disease would no longer be effective.

Ontario must act now to prepare: providing education to primary care providers, where most Ontarians start their path to diagnosis; making more effective use of specialists' limited time; bolstering our MRI and PET scan capacity; and investing in research for emerging screening techniques, such as blood-based bio-markers and retinal scans.

# ADVOCATING FOR A MORE DEMENTIA-FRIENDLY ONTARIO

The Ontario Dementia Care Alliance is committed to improving dementia care.

In December 2021, the Alzheimer Society convened a panel of 21 experts across the spectrum of dementia care and asked a simple question: what are we doing wrong today in Ontario? This feedback led us to 77 fully costed recommendations, which we compiled into our Roadmap Towards a Renewed Ontario Dementia Strategy.

Throughout 2022 the Roadmap was promoted by ASO to elected officials, policy advisors, external stakeholders, and media. We met with nearly 200 major party candidates during last year's provincial election, and held one-on-one meetings with 41 Members of Provincial Parliament following the June vote. All major parties included some sort of commitment to improve dementia care in their election platforms, and when the government was re-elected it followed through on a promise secured by ASO to increase funding for the Ontario Dementia Strategy by \$5 million annually.

That wasn't enough, so we didn't stop there. Targeted lobbying efforts have caught the attention of senior civil servants, political staff, and Cabinet Ministers within the provincial government.

We look forward to celebrating major investments in next year's annual report.



ASO staff and Dr. Sharon Cohen, Medical Director with the Toronto Memory Program (second from left), present research findings at Queen's Park in September 2022

The Roadmap continues to serve as ASO's flagship advocacy document. Multiple members of our expert panel expressed gratitude that such a project was finally being undertaken, saying that it was "about time". So, we decided not to disband the panel after the Roadmap was launched. The end result is a panel of 17 leading experts in dementia care across the province: the Ontario Dementia Care Alliance (ODCA).

The ODCA provides proactive, tangible recommendations to the provincial government on how it can meaningfully improve interactions Ontarians affected by dementia have with the health and long-term care systems.

Launched in December 2022, the ODCA released its inaugural policy document just a month later.

We're excited to see where this takes us and honoured to be working alongside the brightest minds in dementia care to build a more dementia-friendly Ontario.

# NAVIGATING THE PATH FORWARD

Right now, we have an incomplete understanding of Alzheimer's disease and dementia—more needs to be done.

In September 2022, the Alzheimer Society of Canada released "Navigating the Path Forward for Dementia in Canada: The Landmark Study #1." This report outlined that actions to reduce risk have the potential to change the future of dementia in Canada, if governments act now.

By the year 2050, more than 1.7 million Canadians are expected to be living with dementia, with an average of 685 individuals being diagnosed each day.

# The Landmark Study aims to achieve the following:

- 1. Clarify the path forward. The first objective of the report is to update public knowledge of dementia numbers across Canada and how we expect these counts to change over the next 30 years.
- 2. Improve knowledge. Dementia is a complex condition with many established risk factors. This report aims to break down the complexity and highlight key

areas for risk reduction.

- 3. Advocate for individuals, families, care partners, and service providers. Most individuals who develop dementia do not face the challenge alone. Family, friends and neighbours often help support people living with dementia. The people contributing both formal and informal care need support and resources.
- 4. Create action. Inspire individuals, researchers, health-care providers, funding agencess, and the various levels of governments to support in 1000 to varid programs and policies that promote

better brain health for all.

5. Push for change. There is a need for action: more dollars for research, changes to our care systems, recognizing and reducing discrimination, stigma and stereotypes, and implementing equitable solutions for the challenges that come with the onset of dementia.



"The numbers generated by this report are staggering."

The impact of dementia on Canada's health-care system will be huge. The time to act is now.

You can read the full report here: <u>alzheimer.ca/en/research/reports-dementia/landmark-study-report-1-path-forward</u>



You can do something about dementia.

**DONATE TODAY** 

www.alzheimerww.ca

**Contact Information** 

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Kitchener Office - 831 Frederick St. N2B 2B4 - 519-742-1422

Guelph Office - 202-25 Wellington St. W. N1H 7T9 - 519-836-7672

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