

# Alzheimer *Society*

PETERBOROUGH, KAWARTHA LAKES, NORTHUMBERLAND & HALIBURTON

## *Annual Report* **For the Fiscal Year 2013-2014**

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Help For Today. *Hope For Tomorrow...*

**Alzheimer Society of Peterborough, Kawartha Lakes,  
Northumberland and Haliburton**

***Vision:*** *To be a leader in the Alzheimer Movement and recognized by our community as an essential provider of dementia-related services and support.*

***Mission:*** *The Alzheimer Society of Peterborough, Kawartha Lakes Northumberland and Haliburton is a person-centered agency dedicated to advocating for and improving the quality of life for those affected by Alzheimer's disease and other dementias throughout their journey.*

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## **Report of the President and Executive Director**

Yet another year has passed and once again we are proud to report on the excellent work completed by the people of our organization. We continue to grow in our ability to serve more people, and we continue to bring higher quality to our services. These accomplishments can only happen with the contributions of all our teams - volunteers, staff and donors. Your continued passion keeps us moving onward and upward.

We are also appreciative of all of our community partners who join us in serving the needs of those affected by dementia. You help in so many ways. Please know our clients are in a better place because of your continued support.

Unfortunately, we continue to see higher volumes of clients with increasingly urgent needs. As a team, we remain in a difficult situation as we try to balance needs and wants within existing resources. And yet, we have met the challenges head on, frequently re-visiting how we deliver our services to ensure we can be available for as many clients as possible. Our team meetings continue to focus on increasing our capacity by redesigning our services and practices, and by expanding roles for volunteers.

Please take a moment to read through this Annual Report. We hope you will share in our many successes, and consider how you can commit to helping us meet the future growing impact of dementia that faces us.

Thank you for supporting our local Alzheimer Society.

Colin Chambers

President

David Webster

Executive Director

## Organizational Overview

*Who We Are:* We are a non-profit charity that provides local services to support those affected by Alzheimer's disease and other dementias.

*What We Do:* We provide a basket of services designed to support those travelling the dementia journey.

*How We Do It:* We work in partnership with those affected by dementia through individual and group support activities, education programs, and advocacy.

### *Our Clients:*

- Individuals diagnosed with dementia are just like you and me – they deserve respect – they are individuals living with a disease, they are not defined by their disease
- Individuals diagnosed with a dementia are not victims of the disease; they are people who most likely will choose to live as healthy a life as possible, choosing to continue an active role in their community
- Caregivers for those diagnosed with dementia are people from all walks of life; it is likely that many of us will be a caregiver for someone who is diagnosed with an illness at some point in our lives



## **Programs and Services**

We provide information and support for clients in the following areas:

- Understanding Alzheimer's disease and other dementias, its symptoms and progression
- Strategies for living well after diagnosis
- Understanding and interpreting healthy brain strategies
- Increasing safety for persons with dementia
- Reducing stress
- Dementia education for children, youth and family members
- Navigating the health care system
- Understanding options for care and transition to long term care
- Advanced care planning
- Researching and advocacy

Our services include:

- Support and education for individuals and families, tailored to their unique situations
- Support and activity groups for persons with dementia and their care partners
- Friendly Visiting Program (Peterborough City/County only)
- MedicAlert® Safely Home® Program
- Education programs for individuals with dementia, care partners, professional and semi professional caregivers, and community groups
- Library loan service of resource materials
- Step Out Walking Club

## **Outcome-Based and Client-Focused Programs**

We anticipate the following outcomes from our client support activities:

- With early detection of dementia, our clients are provided with an opportunity to adjust to the diagnosis and to participate actively in planning for their future, and are provided with an opportunity to remain engaged in their community for a longer period of time
- Our clients will be more educated about healthy living that could result in a delay of the onset of the disease; earlier diagnosis translates to earlier access, and earlier access translates to earlier diagnosis, with the potential to slow down the development and progression of the disease through an increased connection to community resources
- Our caregiver clients will be provided with education and skills that will support them through their struggles with the overwhelming emotional and financial hardships of providing care
- Our caregiver clients will be better able to cope with their responsibilities, which may translate to being able to care for their loved one, in their home environment, for a longer period of time
- Our clients will be educated about, and supported in obtaining access to, community support services within the health care system that can help to alleviate pressures and may delay the need for admission to a long-term care home

## Meeting the Vision of the Central East LHIN

We are pleased to be able to report that we are delivering programs that align with the mandates of the Central East LHIN. Our service outcomes will help the LHIN in their goal to reduce wait times for service, reduce hospital visits, and delay the need for long term care admission, by providing supports that promote greater chances to remain at home in better health for longer periods of time.

As the LHIN continues to investigate ways to deliver services to seniors in more effective ways, we continue to be able to support them when asked for contributions based on our expertise in working with individuals and families affected by dementia. We have been invited to participate in planning discussions for initiatives such as Behaviour Supports Ontario, Peterborough Health Links, and GAIN clinics. We have also seen an increased activity level in our education programs being delivered to staff at various long term care homes through the Behaviour Supports Ontario initiative.

We continue to advocate for individuals and families affected by dementia. Here are some excerpts from our *Dementia Evidence Brief*, as presented to the Central East LHIN:

- Dementia is a core issue impacting Ontario's health and social system
- Today, close to 24,600 people over the age of 65 in the Central East LHIN region are living with dementia; between 2012 and 2020, the total number of seniors with dementia in the region is expected to increase by 33% to more than 32,700 people, intensifying already existing strains on community resources, emergency departments and acute care hospitals
- People with dementia are at a high risk of complexity and hospitalization; people with dementia face extraordinary challenges of



self-managing their general health and chronic conditions due to memory problems, perception of symptoms, decision-making and expressive language, resulting in potentially treatable conditions being exacerbated

- People with dementia are prone to cycles of emergency department use and hospitalization, stabilization, discharge to home, poor self-management, deterioration, and readmission to the hospital; the destabilization of other chronic diseases leading to complexity and avoidable hospitalizations has been called “the dementia domino effect”
- Individuals with dementia are also at a heightened risk of delirium and functional impairments in response to acute illness
- Research in Ontario shows that seniors with dementia are intensive users of health-care resources; people with dementia are twice as likely to be hospitalized compared to seniors without the disease, twice as likely to visit emergency departments for potentially preventable conditions, more than twice as likely to have alternate level of care days when hospitalized, and nearly three times more likely to experience fall-related emergency room visits
- Dementia is the key diagnosis related to hospitalization with alternate level of care days, with one out of every four Canadian seniors hospitalized in 2009/10 having a diagnosis of dementia
- Evidence shows that people caring for someone with dementia provide 75% more care hours than other caregivers; they report feelings of distress, anger or depression, or inability to continue to care, in one out of 5 cases
- A recent study determined that rates of caregiver distress were five times greater among individuals caring for seniors with moderate to severe cognitive impairment compared to those caring for seniors without cognitive impairments

## **Our Key Education Focus: Getting an Early Diagnosis of Dementia**

We are often asked, “why get an early diagnosis?” We know that dementia is a progressive degenerative disease which remains incurable, and that medications might work well for some, but not for everyone.

There are many reasons why people might avoid getting diagnosed, but all too often it’s because they’re fearful of dementia and are unaware of the benefits of a diagnosis. That’s why, this past year, the Alzheimer Society launched a nationwide campaign to promote the benefits of early diagnosis and help people understand there is life with dementia.

As many as 50 percent of Canadians with dementia are not diagnosed early enough, losing precious time when care and support can make a tremendous difference in their quality of life and avert unnecessary crises for their families.

But fear and stigma continue to be huge barriers to seeking help. In a recent Nanos survey, 60 percent of Canadians polled said it would be harder to disclose if they, or someone close to them, had Alzheimer’s disease compared to other diseases because of the social stigma associated with mental health issues.

Earlier diagnosis opens the door to important information, resources and support through local Alzheimer Societies, which help people with dementia focus on their abilities to remain independent in their homes and communities longer. With early diagnosis people can access medications that, although not effective for everyone, have the greatest impact when taken early. On a practical level, an early diagnosis gives someone the chance to explain the changes happening in their life to family and friends and allows families to plan ahead.

“Seventy-four percent of Canadians know someone with dementia and more and more Canadians will continue to develop the disease. We want to make sure they are getting the help they need at every stage of the disease” says Mimi Lowi-Young, CEO, Alzheimer Society of Canada. “As devastating as the news can be, early diagnosis brings relief to families, gives them control over their situation and adds more years of living active and fulfilling lives”.

## Education Activities

The Society provides educational support to individuals and families, professionals, community partners and various community groups – anyone directly or indirectly affected by Alzheimer’s disease and other dementias.

Educational activities are provided to the following priority groups:

- Individuals living with dementia and their care partners;
- Staff and volunteers of the Alzheimer Society
- Staff and volunteers of community agencies and long term care homes providing service to those affected by dementia
- The broader community who indicate an interest in knowing more about dementia

## Dementia Champions and our Political Strategy

This past year we have introduced a new role to support our Political Strategy. *Dementia Champions* are both individuals living with dementia and caregivers, people who have first-hand experience of the dementia journey, who have joined in visits to politicians at municipal, provincial and federal levels. The purpose of these visits has been to increase awareness about the need for changes in our health care system and social services to support the needs of those affected by dementia in our local communities.



**FocusON**  
**dementia**

*"I became a Champion for Dementia to help make a difference. You can too! Join me today and become a Champion!"*

Susan Parish  
Dementia Champion

The image features the 'Focus ON dementia' logo in blue and yellow text. To the right of the logo is a circular graphic containing a yellow map of Ontario. Further right is a photograph of Susan Parish, a woman with short grey hair and glasses, wearing a patterned shirt. Below the logo and map is a quote in italics, and below the quote is her name and title.

## **Client Activities**

Our services are provided...

- “at the right place”, in locations throughout Peterborough City and County, City of Kawartha Lakes, Northumberland County and Haliburton County
- “at the right time”, with efforts to engage with clients as early as possible in the journey, throughout the journey of the disease progression, and when the needs become very complex

This past year, there has been an increase in the complexity of needs and urgency for support from our clients.

## **Client Picnics**

Following a successful revamp of our client picnic in Kawartha Lakes, this past year we introduced a second location in Peterborough. Both events were very well attended, and successful in bringing together clients for an opportunity to socialize, eat and dance ... while being able to be “live for a short while” without any mention of dementia.



## **MedicAlert® Safely Home®**

The Alzheimer Society of Canada is proud to partner with MedicAlert® Foundation of Canada to provide MedicAlert® Safely Home® (MASH). While originally created to help emergency responders provide treatment quickly and effectively for those people who couldn't speak for themselves, the service can also help when people with dementia go missing.

Now, with MedicAlert® protection, there is an effective way to identify the person who is lost and bring the family back together. Medically trained specialists are available 24/7 to immediately supply police and emergency responders with physical descriptions, emergency contacts and critical health information. MedicAlert® information is engraved on the ID worn by the member. And family members and caregivers are notified when a situation happens and a member is found.

### **Introducing the Finding Your Way Program**

The Finding Your Way program is designed to raise awareness of the safety risks experienced by people with dementia. One of those risks is getting disoriented and going missing.

The Finding Your Way program is designed to prevent such incidents from happening. It works in tandem with the MedicAlert® Safely Home® program which helps identify people with dementia who are lost or disoriented.

This program includes a tool kit for caregivers to create a plan that helps to ensure the safety of people with dementia without depriving them of their independence or dignity.

To review the toolkit, visit: <http://www.alzheimer.ca/en/pklnh/Finding-Your-Way>

## **Group Programs Continue Strong**

We continue to host our successful group programs, more than 30 monthly opportunities to gather and discuss issues relevant to the dementia journey, socialize with others on the same journey, and participate in healthy brain activities.

- *Changes:* A group for persons with early-stage dementia who are able to attend independently;
- *Milestones:* A group for persons with middle-stage dementia whose care partners need to be available;
- *Caregiver Support Group:* A group for caregivers of individuals with dementia;
- *Activity Club:* A group for persons with dementia and/or caregivers, with a focus on healthy brain activities.

## **Social Clubs**

This new form of gathering was originally an opportunity for former caregivers to meet and socialize, former clients who were no longer associated with the Society's Ministry-funded programs in Peterborough and Kawartha Lakes, and who wished to maintain friendships formed over the years. This program continues to expand, and now includes individuals and family members still being affected by dementia. The Society only provides contact information for clients wishing to join this group, without providing any direct support to the groups.

## **Step Out Walking Club**

After a successful pilot in Kawartha Lakes, we have introduced a second Walking Club in Peterborough. This has been a wonderful expansion of our Friendly Visiting Program, not only linking those living with dementia with a "walking buddy", but also linking them to others in a social setting, and providing them with opportunities to be active outdoors. Fresh air, heart healthy activity, and socialization – good for anyone!

## Volunteers

Volunteers play an integral role in allowing the organization to meet the demand for service! This year we have been working on several new initiatives.

### *Client Advisory Committee:*

New this year, the Client Advisory Committee is a standing committee reporting to the Board, that has become critical to ensuring we have first-hand experience helping guide us in what we do. Members of the committee are individuals living with dementia, representing our 4 counties. They have participated in strategic planning, political engagement, and community presentations.

### *Volunteer Callers:*

Expanding from a pilot last year, our Volunteer Caller program helps in making calls to clients, allowing trained volunteers to follow-up with those clients who may not need a great deal of support at the time. This helps us keep in touch, and helps identify when circumstances may be changing and connects clients with additional support when their situations become more critical and urgent.

### *Education Ambassadors:*

Through a new program, we are currently training Education Ambassadors who will be able to make presentations in the community, representing the organization at health fairs and seniors events, and allow us to reach out to those not yet diagnosed or not aware of our services. This will contribute to earlier diagnosis, earlier access to supports, and reduced impact on the health care system later on.

In addition to these programs, volunteers also play a key role in meeting other activity needs, including support group facilitation, administrative support, fundraising event support, friendly visiting and step out walking club, and Board of Directors and committee members.

## Fund Development and Donors

*Generous gifts go a long way!*

Over the past year we were grateful to have received a number of major and planned gifts, totalling more than \$225,000. These funds will be placed into our reserve fund account, and will be available for short term and long term future needs that may include new premises, increased staffing, and/or new programs not funded by the Central East LHIN.

*Increased Fund Development Staff*

Recognizing that the only way to help ensure we can continue to provide services to meet the current and growing demand, we made the decision to hire a second part-time staff person. This additional resource will allow us to expand our current fundraising activities, and foster development and growth of major and planned giving programs.

*Thanks to all our supporters!*

This past year we have seen continued growth in our support from both past and new members to our family, demonstrated by more unique events in our communities, more individuals and families making donations. We are grateful for all these contributions that allow us to continue providing service at no cost to our clients.





## Partnerships

Relationships with our partners continue to play a critical role in allowing us to deliver our client services – we are truly grateful!

- We receive referrals from community partners, linking individuals and families needing help to our organization
- We refer our clients to community partners for additional services
- Community partners allow us to use space at no cost for delivery of programs and hosting of meetings
- Community partners provide us with respite services, increasing participation of caregivers in our group programs

## Communication

We developed a *Communication Strategy*, helping us to develop consistent messaging throughout the organization, and helping us to ensure we are delivering the most appropriate information to all of our stakeholders.

We completed a major revamp of our *website* that now has much more information for a broader audience – easier to navigate with much more content – have a look! [www.alzheimer.ca/pklnh](http://www.alzheimer.ca/pklnh)

While we still continue to distribute a newsletter twice each year, we have also introduced an *e-newsletter*! Shorter, and shared monthly, this format allows for subscribers to have more frequent contact with our organization – keeping in touch with all the current news. Let us know if you would like to receive a copy ([info@alzheimerjourney.ca](mailto:info@alzheimerjourney.ca)).

Coming soon – plans are underway for our launch into *social media* through Twitter and Facebook. This will offer even more ways to keep in touch with our organization and others who share an interest in dementia!

## On The Horizon

Our Strategic Planning Session was held in June. From this planning process, we confirmed several priority areas for moving forward:

- We need to close the current gap between those who live with dementia and those receiving our support
- We need to prepare for the pending “tidal wave” of clients as the baby boomer generation ages
- We need to address gaps in service for individuals and families not currently served by other organizations



## **Appendix One: Program Statistics and Financials**

Number of active clients (persons with dementia and caregivers) registered with the organization on March 31<sup>st</sup>.

	Mar 31 <sup>st</sup> 2013	Mar 31 <sup>st</sup> 2014
Peterborough County	676	821
City of Kawartha Lakes	657	621
Northumberland County	2,686	335
Haliburton County	127	118
Other	133	179
Total	1,861	2,074

Number of individuals served, by function center, within the fiscal year, in all 4 Counties.

	2013/14
Caregiver Support	1525
Family Support (persons with dementia)	1133
Education (registered clients)	208
Education (non-registered participants)	2535
Friendly Visiting	83

Number of unique individuals served by the organization, within the fiscal year, in all 4 Counties.

2012/13	2013/14
2,782	2,915

## Financials

With client volumes increasing, meeting the funding needs of the organization continues to be a challenge for the future.

***The Society is appreciative of the Central East LHIN who increased their funding level this past year.***

As well, the Society made the decision to hire an additional Fund Development staff person to bring in additional dollars required to meet service needs.

	2013/14 (pre-audit)
Government Funds	\$ 638,879
One-time Government Funds	28,974
Local Fundraising	425,928
Local Misc Funding	27,467
Total Revenue	1,121,248
Total Expenses	940,056
Balance	181,192

Putting the Numbers Together:

	2013/14
Clients Served	2915
Education Learning Series	18
Support Groups (meeting monthly)	30
Government Funding	\$ 638,839
Govt One-Time Funding	\$ 28,974
Local Funding	\$ 453,359
Total Revenues	\$ 1,121,248
Total Expenditures	\$ 940,056

**Appendix Two: Board of Directors 2013/14**

President:	Colin Chambers
Vice-President:	Dr. Robert Kyle
Vice-President:	Michelle Tabour
Secretary:	Joan McCormick
Treasurer:	Sheila Thompson
Past President:	Bob Geddes
Directors:	Ray Johnson
	Dorothy Owens
	Donna MacDonald
	Christopher Rooney
	Judy Matte-Thompson
	Joyce Ferguson
	Carol Urbach

### **Appendix Three: Staff Team 2013/14**

#### **Program Staff:**

Betty Batten	Friendly Visiting Coordinator
Susan Barringer	Client Support Coordinator
Sarah Cook	Public Education Coordinator
Pat Finkle	Client Support Coordinator
Bonnie Fitzgerald	Client Support Coordinator
Carolyn Hemminger	Client Support Coordinator
Lisa Morasse	Public Education Coordinator
Anne-Marie Peters	Client Support Coordinator
Diana Primavesi	Client Support Coordinator
Jennifer Stubbert	Client Support Coordinator
Danielle Vernon	Client Support Coordinator
Sylvianne Young	Client Support Coordinator

Resource Staff:

Betty Batten	Volunteer Resources Coordinator
Nancy Bozak	Administrative Assistant
Debra Bumstead	Bookkeeper
Susan Dunkley	Fund Development Coordinator
Melinda Ferguson	Bookkeeper
Debra McCarthy	Fund Development Coordinator
David Webster	Executive Director

Changes This Year:

This past year, we have said goodbye to Melinda Ferguson, Susan Barringer, Anne Marie Peters and Sylvianne Young. We also have Sarah Cook on maternity leave. As well, we have welcomed Danielle Vernon, Debra Bumstead and Susan Dunkley to the team.

And shortly into the 2014/15 year, we have welcomed Shelby Downer, Anjie Bellini and Denise Ansell to our team as Client Support Coordinators.