

# Alzheimer Society Peel. Winter 2016, Quarterly Newsletter (text only)

## Our Culture of Caring

Alzheimer Society Peel has dedicated over 30 years of commitment to Client Centred care. The people make the difference

My Journey with Alzheimer Society Peel

By Donna Diciccio, Chief Operating Officer

I was introduced to the Society in April 2001 when I began my journey with Alzheimer Peel as Acting Program Coordinator in Brampton. At that time 2 day programs were running and a 3rd in Meadowvale was getting ready to open its doors that June. Counselling had just expanded to 2 sites and there was a full time Education Coordinator, a Volunteer Coordinator and support groups had also expanded to two sites. Alzheimer Society Peel had a staff compliment of 25 full time staff. Events consisted of Coffee Break, a Forget Me Not Harley Davidson Raffle, Hy & Zel's Charity BBQ, Teddy Bear Campaign, Walkathon, Bowlathon and Alzheimer Society Peel held its 4th annual Golf Marathon. I had just come from being involved with Alzheimer Society Muskoka where there was only one staff person and was truly overwhelmed by the services and events offered in Peel. I was proud to be part of such an advanced chapter.

Fast forward to 2016 and I am continuing on my journey with Alzheimer Society Peel but now as Chief Operating Officer overseeing all programs and services within the Society. During my 15 years with the Society I have had the opportunity to help with front line work, be part of management within a day program, deliver education sessions, provide counselling, run the volunteer friendly visiting program, as well as work closely with the LHIN on many different committees and be Acting Chief Executive Officer in the absence of Chris Rawn-Kane. In 2011 Alzheimer Society Peel began to prepare for its first Accreditation. Although I had been involved in other Accreditation processes this was the first for Alzheimer Society Peel and it was exciting to be a part of this. In 2013 Alzheimer Society Peel passed with the highest designation by CARF (3 Year accreditation status). The process began the day after Accreditation for Alzheimer Society Peel 's second cycle in 2016.

At present Alzheimer Society Peel has 5 day programs, 1 respite care home, a bathing program, First Link program, counselling, education, support groups are offered at all 5 sites as well as at Sheridan Villa, and the Behavioural Supports Ontario program which consists of Community Support Workers, Psychogeriatric Resource Consultants and Counsellors. Events

today consist of Coffee Break, Bowlathon, Golf Tournament, Forget Me Not Gala, Walk/Run for Memories, Teddy Bear Campaign and numerous 3rd party events. The Society's staff compliment is 125 (big change from 2001). My role and my passion in life has always been to serve my community and ensure there are services available for all seniors. But as I have come to learn through my time at Alzheimer Society Peel, communities change, needs change and the face of the disease changes. It is important that we adapt and adjust to the times in order to fully serve the community at large. I believe the key to being a good leader is to have a good team. Alzheimer Society Peel is very fortunate to have a talented group of staff and volunteers all of whom make my role as Chief Operating Officer a pleasure. I am honoured and privileged to be part of such an innovative expanding Alzheimer Society that provides "Help for Today and Hope for Tomorrow" in the programs and services offered.

## Upcoming Fundraising Events

Alzheimer Society Peel Bowlathon

April 16, 2016

Get your teams together for another great time at our annual Bowlathon fundraiser!!

To register your team, contact Rosalyn at [r.adolph@alzheimerpeel.com](mailto:r.adolph@alzheimerpeel.com)

Walk For Alzheimer's and 5k unforgettable run

June 4, 2016

Join us at the beautiful Lakefront Promenade Park in Mississauga.

Watch our website for more information about online registration - coming soon.

Or visit [www.events.runningroom.com](http://www.events.runningroom.com)

[r.adolph@alzheimerpeel.com](mailto:r.adolph@alzheimerpeel.com)

## A look at your Multicultural Committee at Alzheimer Society Peel

In June 2011 Alzheimer Society Peel formed a Multicultural Committee to achieve the culturally diverse requirements within Alzheimer Society Peel. The committee consists of a number of staff members that represent the different service areas of Alzheimer Society Peel. The committee meets once per month to brainstorm and create culturally diverse goals and objectives to implement throughout the year; which has included planning and implementing monthly theme days to celebrate different cultures.

## Accomplishments

The committee has been running special theme days that showcase and celebrate one's culture by preparing various culture specific foods, running games, music, clothing, celebrations and customs. Language binders and flashcards along with the staff newsletter have been used as resources to not only help us communicate but to provide better understanding of the different cultures of our members and caregivers.

Alzheimer Society Peel has already celebrated Ghana, Germany, Kenya, China, France, Ireland, Italy, Poland, Portugal, Philippines, India, Canada, England, Mexico, and Nigeria. We have hosted a special Caribbean theme day! Nora's House also organized a 'high tea' with guests to enjoy this British ritual!

In 2013 the committee also launched its "All Around the World at ASP" Boards. You will find pictures of our staff and clients which truly illustrates how diverse the Society is. These boards can be found at each Day Program and at Nora's House and are updated on a semi-annual basis in order to showcase our clients' different cultural experiences.

In December 2014 the committee launched its All Around the World at ASP Multicultural Binder. Here you will find selected countries languages, history, sports, dress-code, food, social etiquette, religions, music and dance along with landmarks and personal care preferences. This binder assists our staff with integrating multi-culturally based programming/activities for clients. The binder also assists our staff in understanding different cultures and how to approach clients of certain backgrounds; not to mention that the binder can be used as an ice breaker to help minimize if not eliminate clients' anxiety levels. The binder has been quite useful in keeping members engaged and allowing them the opportunity to speak about their home countries and various aspects of their cultures  
iPads are also used not only to provide translation services for our staff but to keep clients engaged in programming. Here is a success story from one of our staff members!

"I had one member who wanted to go back to their home town in Scotland. I used the iPad to play documentaries on Scotland and was able to keep this member very engaged. We were able to reminisce about Scotland and were able to see places that were very familiar to this member. The iPads have also been used to play all different types of music relating to their culture. It really lights up our members' faces when we play something that is familiar to them."

## Future Projects

The committee will continue to expand our All Around the World binders, boards, language flashcards, and plan culturally diverse theme days. Our primary goal for 2016 is to build a multicultural based Resource Library that will provide magazines, books and newsletters in different languages. These resources will be used for different programs during the day for our members; i.e. 'Time For You" or during morning and afternoon social.

Multicultural Committee Members: Susie Costa, Deb Downie, Isis Saleh, Krishna Sagoo, Jenny Hall, Heather Daw, Melissa Buskard.

Our goals are to:

- Recognize
- Share
- Understand
- and Respect Cultural Diversity

Stay tuned! We look forward to sharing our experiences with you!

## My Personal Experience as a Sandwich Generation Caregiver

I have been a staff member of the Alzheimer Society Peel for many years, and I started with the Society long before I was ever personally touched by dementia, but 4.5 years ago my father was diagnosed with Vascular dementia, with potential of mixed dementia, at the age of 63, and suddenly I had another role added in to my already hectic life.

I have two school aged children, now aged 10 and 13, but at the time of my dad's diagnosis they were just 6 and 9. Both boys are involved with travelling sports teams. They are busy and active, which is a great thing for young boys to be, but means a lot of running them around for mom, and a lot of weekends out of town as well. I was working full-time when my dad was first diagnosed, but made the decision to drop to part-time in order to find enough time in the day to support both my dad, and my kids. I am also married, and need to devote time to my spouse as well, since I would like to stay married. So now, I am a working mother, wife, and POA /Caregiver for my parent. All of these roles are important and all need my time and attention, but juggling them has been no easy task.

Like many people of my generation, my parents are not together, and so decisions on my father's health care, living arrangements, and finances,

have all fallen to my sister and me. While my dad is in the early stages I have juggled around my schedule to attend doctor appointments with him, get POA and finances in order, made sure he got a Medicalert bracelet, helped him apply for disability pension, helped him appeal the decision when disability pension was denied, and attended some First Steps education so that he would be better prepared to deal with the challenges to come. All these tasks, while time consuming, and I had little time to spare, were relatively easy decisions to make. Other decisions however; weigh heavily on the mind. When supervision becomes necessary where will dad live? This is a tough decision for all families effected by dementia to make, but I think especially difficult when your children are still minors and still need so much of your time and attention. Do I have my parent live with me? How will that effect my marriage, my children, and my sanity? Where will I find the time? Will I make the decisions for him that he himself would have chosen? What level of risks are both he and I okay with? There are no easy answers.

These are very personal choices, and there is no single right way. I believe all adult children caregiver's in this circumstance must weigh out the pros and cons, and make the best choice for them and their families. I have decided, after much discussion with my spouse and children, to not have my father live with me. I am simply not home enough of the time to provide the care that will be needed. Logically, I know this is the right decision for my family, but as a daughter, who loves her parent, the guilt and what ifs are huge. I keep telling myself "just do the best you can for all of them, and solve one problem at a time". Managing one hurdle at a time, and doing some pre-planning has helped to reduce stress levels but the guilt, worries, and un-knowns are still ever present. The word "sandwich" is a good word to describe what it feels like to be squished in the middle between the needs of your children, and those of your senior parent, but I am hoping that like peanut butter, I can make it all stick.

Danielle Farrell, Central West First Link Coordinator

## Care Giving and Compassion Fatigue

Elaine Griffin, Psychogeriatric Resource Consultant for The Alzheimer Society of Dufferin County and Paula Frappier, Geropsychiatry Community Education Coordinator with Homewood and Trellis, facilitated a compassion fatigue workshop for family members caring for individuals living with dementia. This article captures some of their discussion and reflections.

"If a person entered an occupation which required them to be on call 24 hours a day, seven days a week; interrupted their sleep so they were never rested; provided no training but tons of responsibility; offered little or no pay and actually cost them money; and prevented them from having any free time to themselves, no one would judge them as being weak if they said they experienced burnout". (caringfortheaged.suite101.com)

The job title is caregiver and it is a role with many ups and downs. Care giving is a story of love, rewards, duty, exhaustion, depletion and loss. It is often a unique and complicated story. But there can be a cost to this caring. Some people call this compassion fatigue; described as being the deep physical and emotional exhaustion that is experienced when we open our hearts and minds to others.

Francoise Mathieu a leading expert on this topic, reports that people who provide care to persons who are ill or have dementia, over time, may feel drained and numb. The Alzheimer Society has found that many of their caregivers report that they have occasionally "lost control" and have shouted or thrown things at the person they are looking after. They may say "I can't believe that I said what I said, I was never like that before." A group of caregivers brought together by The Alzheimer Society in Dufferin County reported that they have, at times, felt resentful of the person they were looking after and were also frustrated by the system of health care and services. This led them to feel hopeless and exhausted.

In 2001, Parent Magazine reported that "at some point during the years of caring for a person with Alzheimer's, an estimated one half of all caregivers become clinically depressed". The American Journal of Public Health reports that the rate of depression is six times higher in care givers than in non-caregivers. These numbers are expected to increase as demographics change to include more seniors than any other population in years to come.

How can we begin to identify when ourselves or others are struggling and what can be done to help?

Next, offer yourself compassion and forgiveness for the feelings you are experiencing. Remember, you are not alone.

One step toward helping yourself is to take stock of your current stress levels. Monitor your physical state by being aware of headaches, your sleep cycles, and feelings of low energy and exhaustion. Pay attention to

behavioural changes such as avoiding social gatherings, increased irritability, increased use of alcohol or other methods of escape. Take note of your psychological well-being, for example, are you more easily agitated, or depressed? Do you feel resentment or have decreased feelings of sympathy or empathy? Are you unable to feel the joy in life?

Once you have evaluated your situation and health, don't be afraid to ask for support. Asking for help is often a very difficult step for caregivers, as they are accustomed to being the "helper" and not the recipient of support. There are often many people who are willing and able to help out; if not family, friends, neighbours, volunteers, or community agencies, like The Alzheimer Society. Care givers attending support and education groups at The Alzheimer Society report being better able to manage their feelings of frustration and therefore provide better care for their loved one than they did before they had support.

Offer yourself compassion and forgiveness for the feelings you are experiencing. Remember, you are not alone. Some important quotes from care givers include "it's okay to put yourself first" and "calling for support builds a safety net to help you cope." Finding a community group where you can share your thoughts and feelings without being judged is invaluable.

Improved self-care is really integrating the healthy living strategies that many of us already are aware of, but often ignore in times of stress. Basic things like eating well, resting, exercising, scheduling time for fun and taking time to journal will really help building resilience and improving one's ability to cope.

In our latest group education session about compassion fatigue with caregivers, they talked and shared at length about this last step. Many of them found it difficult to get away either due to a sense of obligation, guilt or logistical difficulties. However, the few that regularly plan to take needed breaks, whether it be from one hour here and there, to a week-long vacation, all said that "it is okay to go on that trip or take a lunch break because when you come back you are re-energized and re-fueled and able to give of yourself again and meet challenges in a better frame of mind.

All of the participants in our group agreed that, although it may be difficult at times, when you look after yourself you can be at your best for the people that need you.

## “My Advice To You”

From the Caregiver Retreat Day 2015 attendees

- Try to have some activity each day, particularly if it can involve some social interaction.
- Do not think of what might have been - Focus on what good can still be had.
- Exercise lots of patience
- If a white lie can accomplish getting the result, don't feel guilty.
- Learn to control your emotions and have lots of humor. Give him/her lots of attention and reassurance and love.
- Have no expectations-learn to roll with the punches. Learn plans are at best illusionary, that they are not set in stone...learn to be flexible.
- Start each day anew and hope for the best.
- Learn to adapt-don't think “you know what they did to me today” realize instead that it just happened-depersonalize, it's not about you or me- it just is.
- Don't sweat the small stuff- “let it go”
- Use the day program as soon as possible - makes it easier for adjustment. Don't take no for an answer.
- Reach out to support groups in the community for help, advice and support
- Do not take personal the way the Alzheimer patient is acting up, differently every day.
- If you do not argue with them you will have a better quality of life. Also try to live with humour; it's the best medicine for your health.
- Get some help and you try to have some fun, otherwise you will go to heaven before them.

## How Should We Educate Ourselves to Care for An Ageing Population?

In just two decades, 1 in 4 Canadians will be over the age of 65, with those 85 years or older being the fastest growing group. The good news is that most older adults will live long and healthy lives well into their later years. Indeed, more of us are increasingly coming to recognize that ageing is not a disease but rather a triumph.

At the same time, we are increasingly recognizing that rates of age-associated conditions, such as osteoporosis, dementia and arthritis are on the rise – simply because we are achieving longer life expectancies. And there's a small but sizeable minority of older Canadians who unfortunately face the triple challenge of living with multiple chronic illness, functional limitation and social frailty that put them at the highest risk of repeated hospitalizations, functional dependency, institutionalization and a poor quality of life.

Canada simply cannot produce enough aging specialists to address the unique and varied complex needs that our ageing population will present. Indeed, the “geriatric imperative” is such that all health and social care providers in every setting will need a strong foundation in the care of the elderly.

There is a growing and justifiably alarming concern that this is not being achieved. A study of Canadian faculties of nursing and social work found that few faculty members had a background in gerontology, and few students chose to do their final placements in a gerontological setting. And, according to one study, only 7 of Canada's 16 faculties of medicine had mandatory rotations in geriatrics, when all offer mandated training in paediatrics. What can be done to ensure that every new graduate can capably address the needs of an aging population?

Both large- and small-scale changes are required. At the highest level, we need coherent strategies to plan the workforce of the future so available training, jobs and incentives meet demand. All accreditation bodies need to include well-defined core competencies (knowledge, skills, and attitudes) in care of the elderly to provide evidence-based guidance for educators, learners, and practitioners. Examples include the core interprofessional competencies for gerontology developed by the National Institute for the Care of the Elderly (NICE). Finally, we need to promote research to identify and share which educational strategies work best.

While these changes are increasingly being considered, it is clear that there is much that health and social care faculties can do to advance training in the care of the elderly. Recent experiences in Canada and from abroad provide many helpful lessons.

First and foremost, attitudes and awareness about aging in general greatly influence how students experience geriatrics training. Students must appreciate the aging process, the social and economic realities of older adults, and anti-elder prejudice to put what they're being taught in context. It helps for students to reflect critically on their experiences caring for older adults, and examine their own reactions through exercises such as group discussion and journaling.

We should emphasize the development of effective communication skills with older adults that takes into consideration doing so with individuals who may have cognitive and sensory limitations, as well as the best way to appropriately engage family members in a manner that is both respectful to both them and their loved ones. We also need to ensure that future practitioners appreciate how and when care can be best provided at home versus other settings. With an increasing desire by many to age in the places of their choice, how do we enable this when it is appropriate for not only the affected individuals but also for their family members and friends who will undoubtedly be experiencing both the rewards and challenges that come from caring for a loved one? Indeed, different strategies suit different settings, patients and caregivers.

Furthermore, allowing students to become more familiar with innovative ways of caring for older adults like the gentle persuasive approach – which emphasizes person-centered, compassionate care for patients with dementia – can allow them to broaden their skill sets in far more meaningful ways that can benefit older patients and their caregivers.

Most professional programs recognize that providers need to be patient advocates. The health and social care system for older adults is highly complex. There exists a vast range of so-called alternate types and levels of care. Not all are equally available when needed. And there are diverse government and voluntary organizations providing different types of support to patients and families. Not all are visible and easy to access. While

students and providers can't bridge every gap, they should learn in general about the entire care "ecosystem" even if they can't be exposed in their training to each part, and learn how to help connect people to the right place and the right assistance at the right time by the right provider.

Finally, perhaps the care of the elderly shouldn't be "hived off" from other parts of curricula like we have done with pediatrics, as this may negatively reinforce the idea that aging is a marginal or unusual condition, instead of a natural and important part of life course. Nor should it be scattered among other training, which diminishes its importance. Instead, we should strive for its appropriate integration. Students can learn basic transferable skills in gerontological settings such as long-term care, rehabilitation and even home care settings as much as they could in acute care hospitals. For instance, medical students at one U.S. school who did their internal medicine training with a geriatric focus performed just as well on national exams as those who received more general training.

Finally, we need to end describing the ageing of our population as a "silver tsunami." This term suggests that our coming of age will be a brief event that we never saw coming and that will likely lead to our overall demise. In fact, where Canada expects to be in 20 years is where Japan is already at. And the health and social care systems are already, albeit slowly, preparing and adapting – we just need to increase the pace of change, and make sure efforts are coordinated, appropriate, effective and enduring. Ultimately, we really need to understand that training our current and future health and social care professionals well in the care of the elderly is not a survival strategy; indeed, it's an opportunity to elevate the standard of care they provide and, we will expect, increase their satisfaction and engagement in the care of their patients, and assure that the changes we are making will support the overall sustainability of our health and social care systems for years to come. n

Thom Ringer, JD Mphil – is a Medical Student at McMaster University and contributor to the National Seniors Strategy Report.

Samir Sinha, MD, DPhil, FRCP – is the Director of Geriatrics at Mount Sinai and the University Health Network hospitals and the Architect of Ontario's Seniors Strategy

A special thank-you goes out to our sponsors who made our 4th Annual Caregiver Retreat possible. Our caregivers enjoyed a much needed day of rest and recharging thanks to generous donations provided by Attune Aging Strategies, First Class Homecare, Nurse Next Door, Tena, East Side Marios, and the Earnscliff Aqua Fit group.

Thank you to all those who supported the Alzheimer Society Peel Coffee Break initiatives. This year we raised over \$30,000

### Have you included Alzheimer Society Peel in your Will?

If you would like to make a gift to Alzheimer Society Peel, either now or in your estate, please consult with your legal and financial advisor to ensure that you will receive all the tax benefits possible. We are also available to consult with you about how a gift may be directed or recognized.

For more information please call us at 905-278-3667

### Meet Our Sponsors

If you are interested in becoming an Alzheimer Society Peel sponsor, please contact: Brandi Deimling  
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Alzheimer Society Peel accepts donations by cheque or credit card (VISA, MasterCard or American Express) in the following manner:

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Please make cheques payable to Alzheimer Society Peel.  
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4. E-mail: [n.bhamra@alzheimerpeel.com](mailto:n.bhamra@alzheimerpeel.com)

Being a part of the Alzheimer Society Peel donor family allows you opportunities to partner with the Society to further grow our exceptional programs, and provide greater services to a growing number of individuals affected by Alzheimer's disease and related dementias.

Alzheimer Society Peel is fortunate to be a part of a greater Alzheimer Society network, which includes a Provincial (Alzheimer Society Ontario) and National (Alzheimer Society Canada) chapters. Many individuals are under the notion that by supporting these organizations, they are supporting Alzheimer Society Peel. Although all chapters believe in assisting those affected by the disease, donations made to any other organization will not arrive in our chapter.

By giving directly to Alzheimer Society Peel, you are entrusting that your donation will immediately aid current and future clients and families to receive services provided by the Society that you have experienced and trusted. We ask you to share your support with us and allow your donations to accompany those on this journey of Alzheimer's disease or related dementia.

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Nora's House  
905-232-6016

E-mail: [n.bhamra@alzheimerpeel.com](mailto:n.bhamra@alzheimerpeel.com)

Website: [www.alzheimerpeel.com](http://www.alzheimerpeel.com)

Office hours: Monday to Friday  
8:30 am - 4:30 pm

If you, or someone that you represent, has a disability and needs accessible services, information in an alternate format, or any other accommodations, please contact

Danielle Farrell at 905-792-1319 Ext. 710.

We will work with you to make appropriate arrangements.