

In the Loop

Société
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SUMMER 2019

RUNNING TO RAISE ALZHEIMER'S AWARENESS: ONE MAN'S INSPIRING STORY

THE GOVERNMENT OF CANADA RELEASES
CANADA'S FIRST DEMENTIA STRATEGY

SHARING YOUR CAREGIVER'S STORY

HOW TO KEEP DEMENTIA TOP OF MIND
THIS FEDERAL ELECTION

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SUMMER 2019

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In the Loop

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112-2719 Gladstone Street, Halifax, Nova Scotia B3K 4W6
902-422-7961 or 1-800-611-6345 (toll free within NS)

The Government of Canada Releases Canada's First Dementia Strategy

John Britton, CEO

Since the Government of Nova Scotia announced the Provincial Dementia Strategy in 2015, the Alzheimer Society of Nova Scotia has been working diligently to expand services offered in line with strategy to an impactful effect.

The statistics speak for themselves. Thanks to collaboration with the Department of Health and Wellness and the subsequent growth in programs and services over 200 public education sessions, 26 caregiver monthly support groups, 20 Family Caregiver Education Series sessions, and almost 3000 calls to InfoLine happened on the toll free and confidential telephone support service all just in the last year.

The 17,000 Nova Scotians living with dementia, or family and friends who are impacted, are benefiting from better access to targeted services that can impact their lives in significant ways.

Collaboratory the Government of Nova Scotia and ASNS are building capacity for improved services each year and now there is news from the Government of Canada about a nationwide approach. "A Dementia Strategy for Canada: Together We Aspire" was officially announced on June 17, 2019. As the first-ever strategy for Canada, the plan outlines a commitment to advance prevention activities, therapies, research, and quality of life initiatives for all Canadians living with dementia.

The strategy will address the overwhelming scale, impact, and cost of dementia in Canada through three key objectives:

- Prevent dementia
- Advance therapies and find a cure
- Improve the quality of life of people living with dementia and caregivers

The strategy is bold, aspirational, inclusive, and outlines a comprehensive approach to multi-faceted dementia care.

You can read more about the National Dementia Strategy at www.canada.ca.

It is early days, but such focus on dementia on a national level is great news for our communities. It is a milestone for Canadians living with dementia, their partners in care, and their families and friends.

Alzheimer InfoLine | 1-800-611-6345



We're here to help

The Alzheimer InfoLine is a confidential phone service provided by our team of knowledgeable and caring staff.

We provide information, support, and referral for persons with dementia, families, caregivers, and professionals.

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Running to Raise Alzheimer's Awareness: One Man's Inspiring Story

Mark Sharkey, Coordinator, Community Giving

Despite a diagnosis of early onset Alzheimer's disease last year, nothing is stopping Alan Main from staying active. This spring Alan ran in the Blue Nose full marathon as part of the Alzheimer Society of Nova Scotia's Charity Challenge team with a time of 4 hours and 49 minutes.

A diagnosis can be difficult for anyone and comes with unique challenges, but conquering challenges seems to be where Alan thrives. Alan was always an athletic individual winning races in both primary and secondary school, but as he reached university and met his lifelong partner Brenda, he extended the distances for the love of running and stopped sprinting. With awareness that things will be harder now, Alan and Brenda have developed strategies that work for them so he can continue doing the things he loves. Together they attended the Shaping the Journey program where they learned the importance of exercise and doing things that open themselves up for success.

For Alan the physical part of the running is easy, but the logistics is the hard part. A solution he found was using the Find My Friends app on his cellphone for his training runs. It provides comfort for Alan knowing he can find his way back to Brenda or call if he needs help, and it also provides comfort for Brenda knowing she can login to see where he is.

In the middle of peak training Alan faced his biggest challenge in preparation for the race – an infection in March. “By the time I recovered I only had a month to get back into shape,” Alan shared. Against all reasonable advice from family and friends, Alan found a training program to run a marathon in a month. “It would have been easier to just say ‘not this year’ to the marathon, but so many family members had donated to support my run, so I had to do it,” Alan explained. “It was so great to see contributions from cousins we only talk to once in a while, and other family and friends hand us a \$20 bill saying ‘I don't know how to work the internet but I support Alan,’” said Brenda.

On race day Alan faced a few bumps in the road, but nothing that stopped him from finishing. “I was three minutes behind the starting gun and was at the absolute back of the pack. I had to push to get up to runners at my level, all while contending with the 10 km runners coming up from behind,” Alan explains. Due to the hills on the route, many consider the Blue Nose Marathon to be one of the hardest in North America. Fortunately Alan loves the hills, “I don't know what it is, I think it is the challenge of conquering a hill!” he exclaims.

One of the best parts of running the Blue Nose Marathon for Alan was having his family there to support him. His brother, sister-in-law, niece, and nephew planned a vacation to Nova Scotia to cheer him on during the race. They set up along different spots along the race and then were all there with his mother June at the finish line.

The next challenge on his list is the Aylesford Lake Triathlon. To ensure Alan can focus on his race, they will confidently ask for an accommodation from race officials. As he prepares for it, Brenda explains that his biggest issue is that he forgets he is now a good swimmer. “It can be hard for his swimming coach when Alan thinks back to the days when he was a weak swimmer, but I calmly remind him, and then he’s back in the water and in form,” she said.

Every step of the way for the past 39 years, Brenda has supported Alan. When she notices Alan is having a hard day, she encourages him to put on his shoes and go for a run. “It really helps when he gets back. He comes back calm and better able to face the rest of the day,” said Brenda. “In my caregiver support group some people talk about how much trouble their partners have sleeping, but I never find that a problem for Alan after a run or 50 km bike ride!”

Alan shares the following advice for anyone trying to stay active after a diagnosis. “Get connected with people who have been doing it longer than you. I joined a local running group and really like the social aspect of running now,” Alan said. “When I shared that I had a dementia diagnosis and some aphasia, the group was even more welcoming!”



Clockwise from lower left: Gentleman Jim the Main family’s dog, Chuck, Paula Main, and June Main hugging Alan after finishing Blue Nose Marathon.

How to Keep Dementia Top of Mind this Federal Election

ASNS Staff

This October Canadians will head to the polls. Even after a late spring announcement of a National Dementia Strategy, there still needs to be meaningful dialogue with candidates, family members, and friends to help make dementia a priority for all parties in this election.

There are several ways you can do this. Once an election is called, please visit www.advocateforalz.ca. There will be tools, tips, and dementia messaging you can use to ensure that Nova Scotians who are on the dementia journey receive support from elected officials.

Don't want to wait until an election is officially called?
Most parties have their candidates selected now.

You can:

- Ask for a meeting with your local candidates by calling, emailing, or sending a letter to their constituency or campaign office.
- Post/share on social media on dementia issues and priorities.
- Share stories and experiences directly with candidates by sending a letter to their campaign office or team
- Ask questions about where a candidate/party stands on issues relating to dementia when candidates or canvassers come to your door.



Do You Celebrate Personhood in Everyday Dementia Care?

ASNS Staff

For three decades, the Alzheimer Society of Nova Scotia has been hosting a provincial conference for health care providers, educators, and families supporting individuals with dementia to connect on the latest research and best practices in the field.

“As former Chair of the Alzheimer Society of Canada (ASC) board, I had the privilege of representing the ASC at a number of national and international educational events. This gave me an opportunity to compare local initiatives with what was happening in other areas. The Alzheimer Society of Nova Scotia conference has always been at the forefront of highlighting innovation in the area of dementia care and treatment, including the value of considering personhood in each individual living with dementia,” says John O’Keefe, regular attendee.

This year at our two day multidisciplinary conference taking place on October 21 and 22, the theme will focus on Celebrating Personhood. At the conference, ASNS will be showcasing the first ever Canadian Charter of Rights for People with Dementia. The development of the charter was co-chaired by Nova Scotia’s very own, Marilyn Taylor.

“I don’t hide that I have Alzheimer’s disease, 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,” says Taylor.

Beyond the conference sessions, there’s opportunity to exchange with a variety of exhibitors and colleagues from across the province. Whether attending the provincial conference for the first time or the 30th, attendees are sure to leave with valuable takeaways.

Monday evening will feature Family and Friends Night, a free event open to the public. A dynamic panel will explore “Living with Change”, and share ways to adapt and live well with dementia. Doors open at 6:00 p.m. with light refreshments, and an opportunity to socialize and view exhibitor displays.

For registration information or to view the complete list of sessions and speakers, visit www.alzheimer.ca/ns.

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Sharing Your Caregiver's Journey

Originally published in the Cape Breton Post in June 2019

Catherine Shepherd, Coordinator, Education and Outreach, Cape Breton

Alzheimer's disease and other dementias can often leave those with the disease and their partner in care feeling isolated. I want you to know there are other people to share the journey with you – you are not alone!

The Alzheimer Society of Nova Scotia offers a network of Caregiver Support Groups open to anyone across the province, including four in Cape Breton. For many people, these support groups can provide a safe environment where you can talk about the disease, share your experience, and exchange strategies for living well. Recently I sat with Johanna Nearing, a Registered Nurse and facilitator of the Glace Bay Caregiver Support Group at Seaview Manor, to share her experience.

“When my dad was diagnosed with dementia, I kept him at home to care for him on his journey. I can appreciate when someone says ‘I feel alone’. Caring can be a difficult job that lasts twenty-four seven. The ability to find care and resources close to home made a positive impact in our family. Being a support group facilitator allows me to share from not only a personal experience, but also as a health care professional,” says Johanna.

Participants in Johanna's support group in Glace Bay are family members who either have someone living in the facility or another facility in the area, people who are living with someone at home, or community members looking for help. Not everyone has a family that can be there to support them, so this group can offer an opportunity to meet others and form friendships with those who understand.

Confidentiality in all Caregiver Support Groups is stressed from day one. “One of the first things we talk about in our meetings is the fact that we don't share any information of those attending with anyone outside of our group. There is still stigma associated with Alzheimer's disease and other dementias, and some people are uncomfortable talking about their loved one with a group of people that are ‘strangers’ in the beginning. They can feel they are doing an injustice in talking about their daily struggles. Our meeting room allows for a closed door and closed curtains providing additional confidentiality,” says Johanna.

A variety of topics are discussed in the support group each week. Each person and situation is unique in some way, so they deal with topics as they come up. One week the group may talk about daily activities that can be difficult for people like sleeping or driving, and the group will offer ideas or suggestions of things that worked well for them so others can try these too.

Another week the group may talk about caring for someone at home and how that can be a difficult journey. Recommendations among the group are often shared such as day programs



for people with dementia that are good for both the person with dementia, but also allowing their partner in care free times for themselves. The group also covers difficult topics like making the transition into long-term care and of course some of the difficult moments that come up too.

“For me, the benefits of the group are that it provides tremendous support to people in so many ways,” says Johanna. “It helps the caregiver know that they are not alone. It teaches caregivers that it’s okay to have some time to help themselves. We provide different education ideas like watching videos to understand how exactly a brain with dementia is changing. This really changes how people look at the disease. We’ve had guest speakers join us and they offer their insight and strategies to help people.”

Each person attending the support group is dealing with the disease in their own way, but this group is there to lean on for support. The group cares about one another and having the support coming back from those in attendance can make such a positive experience. “The information we get from this group we can’t get from a book – it comes from one another!” says Johanna.

To learn more about support groups meeting near you in Cape Breton, call the Alzheimer InfoLine at 1-800-611-6345.

Barrington Group: Building a Culture of Giving

ASNS Staff

For Andrew Creaser, Managing Partner at Barrington Consulting, a connection with the Alzheimer Society of Nova Scotia is a logical one.

When his father was diagnosed with dementia, Andrew watched him change. But it was his mother, the caregiver, that affected Andrew most. “When my father didn’t know anyone else, he still knew his wife, and she was his constant companion and source of security, so he followed her everywhere. For her, the disease was all consuming,” Andrew remembers.

Watching all this unfold had an impact on him. So when he was presented with the opportunity to support the Alzheimer Society he thought it was a perfect fit for him and his company.

Barrington Consulting’s involvement with the Society ranges from entering a team in the IG Wealth Management Walk for Alzheimer’s, to hosting their own fundraising events. Jizelle Makhoul, a consultant with Barrington Consulting, has been planning fun fundraising events such as: yoga classes and wine tastings.



Barrington Consulting Team at the 2019 IG Wealth Management Walk for Alzheimer’s

Recently Barrington Consulting partnered with the Society to conduct an IT review. This was an invaluable gift that has helped the organization support clients and donors more efficiently.

“Working with Andrew and Jizelle has been a pleasure as they are always enthusiastic to support the Society, says Dawn Kehoe, Manager Community Giving, at the Alzheimer Society. “They are an example of how a business can get involved with the Society to fundraise and support Nova Scotians with dementia. I love meeting with new donors and fundraisers who want to get involved but don’t know where or how to start. I have a lot of ideas and I enjoy the challenge of figuring out exactly what type of fundraiser works for each person, business or organization.”

Andrew wants philanthropy to be part of his company mandate. He believes that having employees involved in a cause, leads to better employees. Also, he wants to work with people who are invested in the world around them, and championing a cause is a great way to feel grounded in your community.

“The public needs to know more about the supports and services the Society offers. People need to know that they are not alone after diagnoses and they can live well with the disease. I like that message: that you can live well with Alzheimer’s. That is what I hope to accomplish. I hope I can help the Society grow its awareness so that everyone knows where to turn when dementia enters their lives,” says Andrew.

Andrew implores other companies to call the Society and talk to one of the experienced staff to see how they can get involved. He wants them to know that supporting a worthy cause improves workplace culture, and makes people happier.



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#LetsTalkAboutDementia

Sarah Lyon, Director, Philanthropy

According to the organization, Alzheimer's Disease International, two out of every three people believe there is little or no understanding of dementia in their countries, ADI is the umbrella organization of 94 Alzheimer associations/societies around the world, of which Canada is one.

In Nova Scotia, January is Alzheimer Awareness Month with activities and opportunities to participate in locally. September is when ADI does a worldwide Awareness Month. There is no doubt that there is more to raising awareness and funds to support those with dementia, than two special months. But a designated time in the calendar does mean that a focus on dementia happens in media.

Still, there remains a global problem that requires global action: stigma and misinformation that surrounds dementia.

“Every 3 seconds, someone in the world develops dementia. The number of people living with dementia around the world is over 50 million, which is expected to almost double every 20 years, reaching 152 million by 2050. The annual global cost of dementia is over \$US one trillion annually, which will double by 2030.

Dementia is now widely recognized as one of the most significant health crises of the 21st century.” - ADI

So what can you do locally to support this global conversation? Nova Scotians can:



Talk about dementia! Talking with friends, family members, colleagues helps tackle the stigma, normalises language and encourages people to find out more information, advice and seek help.



Attend an education session (or request one at your workplace/social club) from the Alzheimer Society of Nova Scotia. There are a variety of topics the Society can present on: “Heads up for Healthier Brains,” and “What is Dementia?”



On social media post about the stigma surrounding dementia and where people can go to find out more, A sample post: “Dementia is not a normal part of aging. Learn more at alzheimer.ca/ns #LetsTalkAboutDementia.



Seek support from your family and friends, health and social workers, and from the Alzheimer Society of Nova Scotia. If you are living with dementia: Remember that you don't have to be alone. It is possible to live more positively with dementia than is often the public perception.

If you are worried about developing dementia: Speak to your doctor about any concerns. The Alzheimer Society of Nova Scotia can provide support before and after you visit with your doctor, as well as information on local programs and supports. Call 1-800-611-6345 to speak to someone.

If you are a partner in care: Caring for someone with dementia can be challenging. It is also important to take care of your own physical and mental health needs as this will make a big difference to the wellbeing of yourself and the person you are caring for. Don't be afraid to ask for help. Call the Society to learn more about the education and supports available to you on this journey.



**World
Alzheimer's
Month**

#LetsTalkAboutDementia
#WorldAlzMonth
www.worldalzmonth.org



In the Loop Newsletter Survey

The Alzheimer Society of Nova Scotia is currently reviewing its communications practices to ensure that we are meeting your expectations for information. Your response to this short survey will help us plan for the future and provide you with timely, relevant information in a format that works for you. Please take a few minutes to complete and return this survey. You can send your completed survey back in the mail, fax it to (902)-422-7971, or drop it off at the provincial office. Thank you for helping us serve you better.

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