

# Société Alzheimer Society

NOVA SCOTIA

# **WINTER 2020**

WE NEED TO TALK ABOUT DEMENTIA

THE SILENT EPIDEMIC: PUTTING SUPPORTS IN PLACE THAT ARE CULTURALLY APPROPRIATE

FALLS AND DEMENTIA: WHAT YOU NEED TO KNOW

TRAVEL TIPS
FOR SPRING BREAK



# **WINTER 2020**

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## We Need To Talk About Dementia

#### Catherine Shepherd, Coordinator, Education and Outreach, Cape Breton

Orginally submitted to the Cape Breton Post

The holidays were a time for celebration and family gatherings. It's also when you may have noticed changes in an aging friend or family member, especially if you had not seen them in a while. Did you notice someone's behaviour over the holidays was out of character, like mood swings? Did you notice changes in their ability to perform familiar tasks? We all lose our keys at some point – but misplacing things or putting them in strange places is not normal.

If you noticed a change in someone close to you, it can be hard to tell exactly what is causing it. Early symptoms of dementia can vary between people and symptoms come on gradually. Sometimes people are aware of their own changes, sometimes the first signs are noticed by family or friends around them. Realising that something may be wrong with someone you're close with can be difficult and feel overwhelming; but having the tough conversations and seeking help early can help discover what's causing the symptoms.

That's why this year, we are focusing on the importance of talking about dementia. According to a survey conducted by the Alzheimer Society of Canada, one in five Canadians would avoid seeking help for as long as possible if they thought they had dementia. Unfortunately, this is not surprisingly. There is still much stigma around dementia, so we need to have conversations about the disease to get people talking more comfortably and openly about it.

If you're feeling unsure about how to start the conversation, read along as I share a few tips.

If you have noticed someone close to you showing possible signs, the initial conversation may be challenging to have. Bring up the topic in a space you are both comfortable in where you can speak freely and hear each other clearly. Begin the talk with what you've noticed to see if they have picked up on the same things. Some people might be open to seeing their doctor once you've spoken to them and others may not. Give them time to get used to the information and get more comfortable with sharing their symptoms with the doctor.

Remember conditions such as depression, thyroid disease, or drug interactions sometimes produce symptoms like those of dementia. Bring up your concerns, but ultimately encourage the person to see their doctor to find out exactly what is going on. Dementia is complex and sometimes making the diagnosis can take time as other medical conditions are ruled out.

Finally, one of the best ways to support someone to is to just provide reassurance that you're seeking out their best interests and that you'll be there to support them no matter what the outcome. Remind them that you're on their side and their advocate.

Talking about dementia may not be easy at first, but at the Alzheimer Society we understand what it's like and are able to help you through the process. If you have any questions on how to start the conversation, call our confidential Alzheimer InfoLine at 1-800-611-6345. The sooner you start talking about dementia, the sooner we can help.

# The Silent Epidemic: Putting Supports in Place that are Culturally Appropriate

# Charisma Grace, Project Coordinator, Education & Outreach, African Nova Scotian Communities

In 2014, the government set out to create a provincial dementia strategy; they spoke to Nova Scotians from one end of the province to the other about their experience with Alzheimer's disease or another dementia. From those conversations a provincial dementia strategy was created and launched in 2015. One of the actions from the strategy was to engage '...underrepresented populations to identify needs and develop culturally specific programs and supports.' But what does that mean and how would an organization work on that specifically?

At the Alzheimer Society of Nova Scotia it meant focusing on partnerships and finding volunteer champions within specific communities. The African Nova Scotia Dementia Initiative is a collaborative effort between the Alzheimer Society of Nova Scotia (ASNS) and the Health Association of African Canadians (HAAC). The latter was founded in 2000 with the aim of addressing African Canadian health issues and the system inequities affecting health.

"According to the Alzheimer Association in the United States, People of African descent are two to three times more likely to develop Alzheimer's disease. They call it the silent epidemic," says Kirstie Creighton, Program Development Manager at the Alzheimer Society of Nova Scotia. "Yet there has been no specific support to meet their needs."

This partnership is essential in addressing barriers to equitable health care usually experienced by racialized groups such as the African Nova Scotian communities. "Although HAAC and People of African Ancestry are still waiting for the health system to collect race and ethnicity specific health data, we would like to commend the Alzheimer Society of Nova Scotia for moving forward with the African Nova Scotian Dementia Initiative which clearly addresses a health need." says S. Davis-Murdoch, HAAC co-founder.

The Alzheimer Society is committed to providing supports, programs and services that are culturally specific and tailored to meet the unique needs of African Canadians. The Society has developed, designed and are now implementing the African Nova Scotian Dementia Initiative in consultation and collaboration with HAAC.

The aim of the initiative is to provide culturally specific education about dementia and increase awareness of the programs and services provided by the Alzheimer Society of Nova Scotia. Since launching in August 2019, 10 workshops have been held throughout the province in Whitney Pier, Antigonish, New Glasgow, Upper Big Tracadie, Guysborough, Truro, Birchtown, Shelburne, Greenville, Yarmouth and Halifax.

"Engaging with communities of People of African Ancestry has been a tremendous success," says Davis-Murdoch, "and a positive indication that members of communities desire support for their dementia journey and would benefit greatly from culturally specific programs and services."

Ever evolving, there are learnings from this partnership that can be used to support other diverse populations. It's this quote from a workshop participant the best sums up the need for culturally specific programming: "Excellent Presentation! It was great to have a presenter who looked like me, and who understood and had experience within my culture and life's journey. She was more than competent and knowledgeable. Thank you!"



# Love: The Greatest Gift of All Sarah Lyon, CFRE, Director, Philanthropy



In February, the world has a focus on love through the marketing of Valentine's Day. It starts soon after the stores finish Christmas sales; red, pink, and white items - and shaped like a heart - start to show up on shelves and in flyers. Cupid strings his bow, secret admirers write valentine cards, and lovers announce their love for each other.

Declarations of this love has spanned history and to this day

are still memorialized. Distraught that he was powerless to help one of his wives - Princess Arjumand Banu Begum who was said to be his favourite - Mughal Emperor Shah Jahan made a promise on her deathbed that he would build her the greatest tomb the world had ever seen. And that he did. Finished in 1653, many consider to this day the Taj Mahal in India as one of the greatest romantic gestures in history.

Now a United Nations Educational Scientific and Cultural Organization (UNESCO) site, the legacy of this gesture of love, endures to this day. As one of the most popular tourism attractions in India, the economic spinoff for the city of Agra is immeasurable. Much like the love of the Emperor and his Princess.

Shakespeare wrote sonnets to the Dark Lady, a mistress to whom he loved, but couldn't formally recognize, while Queen Victoria commissioned several monuments to honour her husband Prince Albert.

Yes, love is in the air and we are inundated in February, but only with one expression of love. There are many others. Philanthropy, some say, is a definition of love. Giving to help others, or to help change the community, the environment, or to increase research, is a wonderful way to think about how we can and do, express love.

While Emperor Jahan made his declaration via a building made of marble, and Queen Victoria with bricks and statues, you can make yours through a gift in your will, a donation of stocks, or an insurance policy. With the 'flick of a pen' like Shakespeare, you can write your love legacy, and have an impact on a generation of Nova Scotians on the dementia journey.

For more information, please contact me by calling 1-800-611-6345 ext. 227 or emailing sarah.lyon@asns.ca to request more information.

# Falls and Dementia: What You Need To Know ASNS Staff

As the weather gets colder and the ground freezes over, we all start to feel a little unsteady in our footing. For older adults and people living with dementia, the fear of falling can be more than an occasional thought in the wintertime. Falls can be dangerous and they are not a concern to just brush off, as falls are the leading cause of injury for older Canadians.

Falls and dementia have an intimate connection. While fall risk does increase with age, when the person is also living with dementia, the risk is much higher. According to the Canadian Institute for Health Information, 16% of hospital admissions by seniors living with dementia are fall-related, while for seniors without dementia, that number reduces to 7%.

What can you do to reduce risk of falls for the people living with dementia in your life? Here's some suggestions to get you thinking!

#### **Assess Your Falls Risk**

If you are living with dementia, you may already know that you're at an increased risk. What can you do to manage your fall risk? Ask your doctor for a referral for a Comprehensive Falls Assessment. This assessment will not only consider physical risk, but also environmental factors like if there's a pet in the home or if there's poor lighting. Having a Comprehensive Falls Assessment will help you identify risk factors, so you can put a plan in place.

You will also want to make your home or living environment dementia friendly. Being dementia friendly means the environment is attuned to the symptoms of dementia— like increased imbalance and confusion. Start by removing loose rugs and clutter from the environment, reducing the chances of tripping over objects.

#### **Gather Your Support Team**

Have a team in place to help create on a fall-reduction plan. This can include your doctor, family, friends, and other professionals such as your occupational therapist. Having various people by your side will allow you to assess the risk from different viewpoints. For instance, an occupational therapist will be able to flag risks in living environments that a family member or friend may not even consider.

#### Reduce Your Risk by Strengthening Your Body

Strengthening your body can not only reduce fall risk, but it can also help those who have fallen to make a faster recovery. At the Alzheimer Society of Nova Scotia, we offer a program called Minds in Motion®. It's a community-based social program that incorporates physical activity and mental stimulation for people with early to mid-stage signs dementia and their care partners. The program not only will reduce fall risk through muscle strengthening, but it has the bonus of working out the mind. To learn more or find a program running near you, visit www.alzheimer.ca/ns.

# 7 Things You May Not Know About Vascular Dementia

Vascular dementia is one of the more common forms of dementia, but how much do you know about it? Read on to learn more about vascular dementia this Heart Month.

#### 1. Stroke is a common cause of vascular dementia

Vascular dementia can happen because of damage to the brain from lack of blood flow or from bleeding in the brain. One of the possible causes of this brain damage is stroke. A stroke occurs when blood flow in an artery stops, either because the artery is blocked or has burst. The damage caused by a stroke may lead to vascular dementia.

#### 2. There are different types of vascular dementia

Different conditions affecting the brain's blood vessels can lead to stroke and other kinds of vascular brain damage. This brain damage may also result in vascular dementia. Two types of vascular dementia are subcortical dementia and cerebral amyloid angiopathy.

#### 3. Symptoms of vascular dementia tend to appear slowly and in steps

Someone with vascular dementia may notice changes in their ability to make decisions, plan, or organize as their first symptoms. Other changes may include difficulties with movement, such as slow gait and poor balance. Symptoms tend to appear slowly, and specific impairments may occur in steps, where the person's abilities can deteriorate, stabilize for a time and then decline again.

#### 4. There is no one specific test that can diagnose vascular dementia

If you suspect that you have vascular dementia your doctor will likely perform a number of tests, both physical (like measuring your blood pressure and cholesterol levels) and cognitive (measuring your judgement and planning abilities). Along with a detailed medical history, these tests will provide your doctor with the evidence they need to make a diagnosis.

#### 5. Having a stroke more than doubles the risk of developing dementia

Strokes can be large or small land can have a cumulative effect (each stroke adding further to the problem).

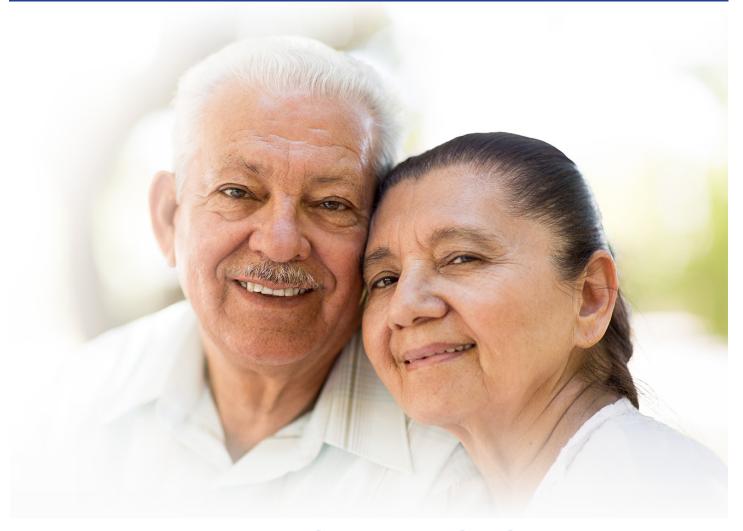
**6.** By managing risk factors for stroke, you can manage risk factors for vascular dementia Controlling the risk factors for stroke can also help reduce the risk of vascular dementia. You can lower your risk of vascular dementia by keeping these risk factors in check: high blood pressure, smoking, stress, unhealthy weight, unhealthy diet, high cholesterol, heavy alcohol use, or drug abuse. Medications may also help control other risk factors like diabetes, cholesterol, and heart disease.

#### 7. Living a healthy lifestyle may reduce your risk of vascular dementia

Since there are currently no medications that can reverse brain damage, it is important to make healthy lifestyle choices (such as being physically active or eating well) for life-long brain health. Even if you have vascular dementia, small healthy changes can help maintain your quality of life. By living a healthy lifestyle, vascular dementia may be prevented, delayed or slowed down.

\*Some content originally published on the Alzheimer Society of Canada's blog

# 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.

Société Alzheimer Society NOVA SCOTIA

# Travel Tips for Spring Break

#### **ASNS Staff**



Whether you are travelling locally by car or flying south to escape the winter chill, getting away can be a great way to break up the cold winter months. As Alzheimer's disease or other dementias progress, changes in abilities can make it difficult to get away, but it doesn't necessarily mean that travel is impossible. Careful planning can help you manage the changes in surroundings and routines.

Read on as we share tips to make traveling an enjoyable break from the norm:

#### Have a plan

- Include your family member with dementia in the planning and share a copy of the itinerary
- Tell friends you are visiting about any changes that may have occurred since your last visit
- Learn about the place you visit to anticipate what you'll need
- Think ahead about activities that may need to be adjusted
- · Consider a holiday package where everything is organized for you
- Have companion cards on hand especially when travelling through airport security. These
  are customizable business size cards with discrete information you can give people you
  come in contact with who might need further information about your companion with
  dementia. If you would like one please contact us.
- Carry recent photographs and have a copy of the name and number of the hotel in your family member's pocket or purse

#### **Simplify**

- Aim for as few changes in routine as you reasonably can
- Try to get a direct flight
- If you're travelling by car for a long distance, consider extending the time to get there and driving shorter distances each day

#### Ask for help

- If possible, have an additional person travel with you to help
- Make sure that your travel agent is aware of any special needs
- Request seating near washrooms
- If you are staying at a hotel, let the staff know about your needs and explain some of the possible difficulties you think you might encounter
- Inform the airline that you are travelling with a person with dementia. You may want to request early boarding, transportation upon arrival, or help with stowing carry-on baggage





Support the Alzheimer Society in your community!

### **FUNDRAISE TODAY**

For more information contact Dawn Kehoe at 1-800-611-6345 ext. 258



Join Team Alzheimer's Scotiabank Charity Challenge May 15-17, 2020

For more information or to join the team contact us at 1-800-611-6345



# Sandra and Deb Walk for Evelyn

### **Morgan Fleet, Event Marketing Assistant**





There are many amazing stories about why Nova Scotians participate in the IG Wealth Management Walk for Alzheimer's, who they walk for and what the walk means to them.

Everyone walks for their own reason. Some walk to honour friends and family members, others to support people currently living with dementia in their community. No matter what the reason, the walk is special and important to each participant.

This year Sandra and Deb will be leading the Sydney Walk with their team Evelyn's Echoes in honour of Sandra's mom. Evelyn was an Avon President's Club member of 30 years and loved to walk. She knew everyone in downtown North Sydney as walking was her way to get out and socialize.

For the past 13 years Sandra and Deb have been participating in the Walk. "Í don't know how I could not walk, and I will continue to walk until the day I can't," says Deb about honouring Evelyn's memory.

"The Alzheimer's Walk is more than just a walk, it's a community of people with shared and vested interest. It's a place of refuge and a safe haven where everyone can come together. It's a platform to raise and build awareness, reach out to others and be heard, and a way to make a difference. If those of us who are affected in some way by Alzheimer's disease or other dementias do not support the annual Walk, who will?" says Sandra.

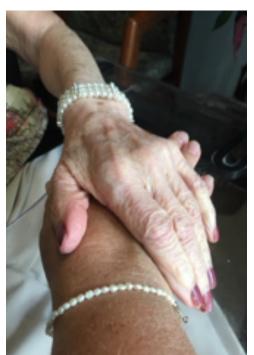
Keep the conversation going, what is your reason for walking? Register for the IG Wealth Management Walk for Alzheimer's today at **walkns.ca**!





# My Mom

## By Darlene Carey, told to Dawn Kehoe, Manager, Community Giving



When we were little we thought our parents were the strongest, bravest, most capable people in the universe. They were our heroes. Then as we got older, we began to see them as the imperfect people we all are.

But even through that new lens, my mother never lost the glint of being my first hero. I would always look at her with awe and wonder.

The most unnatural dynamic is when you have to start parenting your parent. As Jann Arden says, "It's hard to be a mother to my mother." And that is exactly where I find myself.

In 2005, Mom was diagnosed with Frontotemporal dementia at the age of 71. Six of Mom's nine siblings were diagnosed with one form or another of dementia. Three have passed away and three are currently in nursing homes.

Before diagnosis, Mom was living a wonderful full life. Full of family and friends, fun with grandchildren, walking, cooking, camping, bowling, fishing, and travelling. Leading up to Mom's diagnosis, we noticed things changing in her behavior. She began to be paranoid; thinking my sister and I were talking behind her back or planning things without her. She was also becoming disorganized and her personal care began to decline. And for a while we didn't know what to do or where to turn.

Mom would describe her dementia in this way, "I can remember what I ate at my wedding supper, but I can't remember what I ate for breakfast." At this point, she was remembering that she was forgetting.

Mom's diagnosis shattered me, but she met it with humour. She always looked on the bright side of everything. She was quick witted and loved to make people laugh. And because of her example, we use humour to get us through the difficult days.

When the doctor at the Cape Breton Regional Hospital's Geriatric Clinic gave us the news, we were devastated and terrified. The doctor told us to expect further changes in her behaviours, memory, and personality. In contrast to our reaction, Mom reacted with her signature quick wit. She looked at us and said, "Well, I will be fine because I'm tough as nails and twice as rusty! "We all laughed with her.

The Doctor also advised us to look into additional support for Mom and ourselves in order to live well after the diagnosis. It was important for us to realize that this was not a disease to conquer

alone. There was help out there for us. The Alzheimer Society was waiting for our call. I attended an Alzheimer Society education session where a gentleman shared his connection with dementia. During the session he spoke so positively about his experience with his mother that it inspired me to pick up my spirits. I went from the gloom and doom, gray cloud of emotions, to realizing that my mother is still enjoying life. That free program was the wakeup call I needed. It changed how I saw this disease.

Mom lived quite comfortably in her own home for quite a while; however, when I began to feel that things were becoming unsafe for her to be at home alone, I knew it was time to take the next step. I felt she was becoming a danger to herself when she began to leave the heat up full blast in all the rooms and began to burn food. We tried different interventions to keep the heat down. We changed thermostats and unplugged the stove, but that just did not work and she became more and more agitated. After five years of living well at home, I was now faced with tough decisions.

Then, the unthinkable happened, her doctor sent her for a mammogram and the diagnosis came quickly. Breast cancer. She was admitted to the hospital and had a mastectomy. While recovering in the hospital from cancer surgery, we received a call from Northside Community Guest Home. They had an opening. It was one of the most difficult things I have ever done. I had to change my mindset – to remind myself that whatever I did was for her and not for me. I needed to keep in mind that her placement in the nursing home was going to be difficult, however, I was doing this for Mom and not to her.

I was heartbroken for myself, but so happy for her because I knew that this was the best thing for her. She was finally safe. That first day was like the day I took my oldest child to her first day of school. It was all new. We were looking around, encouraging her with our words, saying she will love it here, telling her that she would make new friends, talking to the staff and trying to make sure that they knew 100% of the things Mom liked to do, what she liked to eat, etc. Then, as all parents do on that first day of school, we left her there and reassured her that we would be back.

When I look back on the last 13 years caring for Mom, I can see how and why we made it through. There are a few things we did right. First, we developed good coping skills such as: positive attitude, laughter, open conversation, leaning in to those around you. Second, we took full advantage of the services offered in our community like: home care, seniors' day programs, the Alzheimer Society and our physician.

Now, when I talk about my Mom and my experiences, I try to let family members and caregivers know that they are not alone. My experiences are most likely similar to their experiences. This disease brings with it a lot of challenges. There are a lot of hurdles to jump in order to help our loved ones live their best life.

I know firsthand that making a donation to the Alzheimer Society will help more families find their way through this disease. Donate today to make a difference to a family in your community.

# Société Alzheimer Society

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