

In the Loop

Soci t  Alzheimer Society
NOVA SCOTIA

SPRING 2019

U-FIRST! TRAINING SESSIONS UNDERWAY IN NOVA SCOTIA

DEMENTIA?
LET US HELP YOU
UNDERSTAND

CAPE BRETON GIRL
MAKES IMPACT

SHARING THE JOURNEY



SPRING 2019

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In the Loop

Find the Alzheimer Society on your favourite social media platform:

FACEBOOK: facebook.com/alzheimersocietyns

TWITTER: twitter.com/alzheimerns

INSTAGRAM: instagram.com/alzheimerns

YOUTUBE: youtube.com/alzheimerns

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

Dementia? Let Us Help You Understand

Lloyd Brown, Executive Director

Imagine going to the airport. You have both a feeling of excitement about reaching your destination, and nerves for the anticipated flight ahead. You greet the airline attendant as you check in for your flight and the person at the counter explains your times, gates, and hands you your boarding pass. All of a sudden they read your identification information and ask, “who is the person who needs assistance?” When you explain that it is you because you live with dementia, their demeanor immediately changes and they stop making eye contact. They now only speak to the friend that is accompanying you. The attendant now assumes you are incompetent and you are no longer treated as a person. *This is the stigma Marilyn Taylor and many other Nova Scotians diagnosed with dementia face every day.*

January has been Alzheimer’s Awareness Month and our campaign has been about changing attitudes towards the disease and reducing the stigma that surrounds dementia. We have launched an awareness campaign, “Yes. I live with dementia. Let me help you understand,” showcasing the unique and diverse stories of individuals like Marilyn Taylor living with Alzheimer’s disease or another form of dementia. While there is no question that dementia is a complex disease, it is just one aspect of a person’s life story. Nova Scotians with dementia deserve respect, a good quality of life, and to face less stigma as they go on living their lives.

Research shows that stigma around dementia is rampant. In a survey commissioned by the Alzheimer Society last year, 1 in 4 Canadians said they would feel ashamed or embarrassed if they had dementia, while 1 in 5 admitted to using derogatory or stigmatizing language about dementia. Misconceptions and stereotypes are often the root of stigma. It contributes isolation those living with the disease incur, and discourages their families from confiding in others or getting the support they need. It is important for people to realize that negative reactions from family, friends, and professionals can impact a person’s well-being and ability to manage the changes brought about by the disease.

People living with dementia are entitled to the same human rights as everyone else, but stigma can create barriers and often contravenes these rights. Recently, this led to the creation of the first-ever Canadian Charter of Rights for People with Dementia. The charter is the culmination of work from the Society’s Advisory Group of people living with dementia from across the country including Nova Scotia’s Marilyn Taylor. Its purpose is to make sure people with dementia know their rights, empowers people with dementia to ensure their rights are protected and respected, and makes sure that Canadians know these rights and support people with dementia.

This year take the time to become better informed about a disease that has the potential to impact every single one of us. By working together we can build an inclusive community.

The next time you meet someone with dementia, I want you to clear your mind of any preconceived conceptions you have about the disease. If you’ve met one person with dementia, then you’ve only met one person with dementia. When they tell you they have the disease, ask them, in their words, to help you understand.

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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Sharing the Journey

ASNS Staff

Sharing what you know to others brings about a better understanding. That was the idea behind this year's Alzheimer's Awareness Breakfasts. Speakers shared their journey of living with dementia with 700 guests in Sydney, Bridgewater, and Halifax.

“By creating a space where we could share the facts and faces of dementia, we hoped to increase the understanding of the disease and reduce the stigma surrounding it,” says Sarah Lyon, Director of Philanthropy at the Alzheimer Society of Nova Scotia.

Guests' journey began with someone from the medical field such as a geriatrician or a nurse practitioner who reminded attendees what dementia is, how it presents itself, how a diagnosis is made, and the progression it follows.

From there, guests were introduced to someone with a personal story to share, in Halifax and Sydney it was Marilyn and Faye, two women living with dementia; in Bridgewater the speaker was caregiver Karen Brown. All three spoke about their day-to-day experience with the disease. Finally, different types of community supports such as pet and music therapy were introduced.

Guests enjoyed the practical approach and walked away informed and inspired. Here are a few comments from attendees:

“Range of speakers was great. Dementia is a journey for all so nice to see all sides represented.”



South Shore Alzheimer's Awareness Breakfast

“Karen’s personal account was impactful, moving, and informative.”

“Faye Forbes, an individual with Alzheimer’s, giving a presentation was inspirational and eye opening to how well someone can live with the disease.”

“This is a path we are starting with a family loved one. Knowing where to start is difficult when you don’t know how. This breakfast gave us lots of info on how to get help.”

“Got to learn more in-depth about dementia, the different types, and enjoyed hearing the personal experiences shared.”

“I really enjoyed the holistic approach to how everything was presented from diagnosis to treatment to family caregivers.”

Awareness Breakfasts are held every January as part of Alzheimer’s Awareness Month. The 2020 events will be announced in the fall.

Thank you to everyone who attended the Alzheimer's Awareness Breakfasts. Special thanks to our speakers, our volunteer committee members, and our sponsors who made this possible:

Sydney Awareness Breakfast



Membertou
Trade &
Convention
Centre



Lawtons
DRUGS

PolySteel Atlantic
The Breton Law Group

South Shore Awareness Breakfast



RIDGEWOOD
ASSISTED LIVING

LaHave Seafoods Limited

Halifax Awareness Breakfast



Fall River Law Office
CBCL Limited
Commissionaires Nova Scotia
PCL Constructors Canada Inc.

Cape Breton Girl Makes Impact

Catherine Shepherd, Coordinator, Education and Outreach, Cape Breton

I know we've all been there. It's one of those days where everything is going wrong and you feel like the world's working against you. You don't hear your alarm go off, you're late for work, and you even manage to hit every red light on the way. Then, all of a sudden a small gesture – whether it be the person ahead of you paying for your coffee in the Tim Hortons drive-thru, or a smile from a stranger across the room – turns your entire day around.

The simplest act of kindness can have the biggest impact and that's one thing Monique Cashin wanted to teach her twelve-year-old daughter, Bridget Claire. Monique's great-aunt had Alzheimer's disease and as Bridget Claire got older, Monique wanted to teach her daughter how an act of kindness can make a difference to someone living with Alzheimer's disease or another dementia.

The perfect time came when Bridget Claire was given a real life baby doll for Christmas. Her mom knew there was a need for dolls in local long-term care homes, so she spoke with Bridget Claire about passing it onto someone else once she outgrew it. This past winter, Bridget Claire decided to donate it. ***"I wanted to donate my baby doll to someone living in long-term care because I knew it could bring happiness to the new owner and make a difference,"*** said Bridget Claire.

We know that people living with Alzheimer's disease during the later stages of dementia still respond to a variety of stimuli, so it's important to help find activities that meet the person where they are in that moment. Therapy dolls can be a great way to provide stimulation, companionship, comfort, and help to reduce aggression and agitation. They may bring back happy memories from early parenthood as well. If you are considering dolls, remember to consult your health-care provider first to ensure it's a good fit for the person with dementia. Discuss with your doctor the pros and cons of introducing a therapy doll for your person. If you do introduce a doll, don't forget to stay in touch with your health-care provider to ensure it remains effective as the disease progresses.

After we shared this story on the Alzheimer Society of Nova Scotia's Facebook page, people from all across Canada (and even in Oklahoma in the United States!) contacted us to learn how they can share their dolls. Amazing! With this one simple gesture, Bridget Claire was able to not only bring joy to the person who received the doll, but also inspire hundreds of people across Canada to follow in her footsteps.



Bridget Claire holding her baby doll

Announcements

Say Hello to Lori Baxter



Lori Baxter joined the Alzheimer Society of Nova Scotia in January 2019 as the Coordinator of Education & Outreach for the Tri-County Region. Her role is to offer education and support to persons living with dementia, their caregivers, and the general public in the Tri-County area. She has already been busy visiting long-term care homes, retirement homes, and doctor's offices to let them know that we are here to help. The one comment she has repeatedly heard is 'we really need it'.

Lori holds a Master's Degree in Social Work from the University of Windsor. She lived in Windsor until August 2018, when she moved to Corberrie. While in Windsor she worked for the Alzheimer Society for the past eight years supporting caregivers, a role she really enjoyed. She looks forward to using the knowledge that she acquired during that time to help in supporting the people in her new community.

Meet Connie VanBerkel

Connie VanBerkel joined the Alzheimer Society of Nova Scotia in February 2019 as the Manager of Community Development. She is working closely with the six regional Education and Outreach Community Coordinators around the province from Yarmouth to Sydney. Connie is also collaborating with the 23 Caregiver Support Groups across Nova Scotia.

Connie has a background in Community Development and has worked previously in program management and development, supporting clients in community. She holds a Master's Degree in International Development from Utrecht University in the Netherlands, and in her spare time is an avid reader and traveller. She is a proud mom to three daughters and one bunny rabbit.



Peter Pan Author a Living Legend, *Leaving a Unique Gift Now Can Help in the Future*

Sarah Lyon, CFRE, Director, Philanthropy

The story of Wendy, her brothers, and their adventures with a boy accompanied by a fairy, being chased by a pirate with a hook for a hand, is known to many of us. Peter Pan by author J.M. Barrie is a novel filled with fantasy and magic. It's an emotional tale about growing up that takes the reader on a journey from London to Neverland.

Written in 1904, the story was inspired by five brothers J.M. Barrie met when he was walking his dog in Kensington Gardens. George, John, Peter, Michael, and Nicholas Llewelyn Davies would lose both their parents soon after forming a friendship with Barrie, who would then become one of their guardians, and they would spend the rest of their lives known as "Peter Pan and the Lost Boys."

Many of us were introduced to Peter Pan through an animated Disney movie with the same title. But the story became an international sensation well before that, it was performed on stages, filmed for silent movies, and had sequels. It has been translated into almost 100 languages.

While the story of Peter Pan is one that many of us know, and makes the author a legend, it is the story of who owns the rights to Peter Pan that made J.M. Barrie a living legend.

How often have you seen or read an interpretation of Peter Pan? There is the animated movie, the Johnny Depp Finding Neverland movie, books, and even a peanut butter! Every time it is used, a royalty fee needs to be paid to use the rights.

In 1929, J.M. Barrie, wealthy from his success, made a living legacy gift to the Great Ormond Street Hospital in London. He signed the rights to Peter Pan and the rights to several other pieces he wrote about Peter Pan, Wendy, Hook and the Lost Boys, to the hospital. Barrie didn't give the hospital any money, just a piece of paper and the hope that it would be of help to the charity.

While Peter Pan had been a success by 1929, there was no way for anyone – J.M. Barrie, the Llewelyn Davies children, or the Great Ormond Street Hospital – to know that 115 years later the legacy gift would still be making an impact on the health and lives of children in 2019. And that is what a legacy gift does: it provides for the future. Most legacy gifts happen in the form of a statement in a will that provides an amount – \$500 and up – or a percentage of your estate to a charity of your choice. But legacy gifts can also be stocks, insurances, land, artwork, or the rights to a piece of intellectual property.

What made J.M. Barrie a living legend, is that he made his legacy gift eight years before he died. The Hospital was able to thank him, show him the work his gift would fund, and he was able to tell others about making a legacy gift.

What J.M. Barrie did, and all legacy donors do, is dream of a better world for those who need help. Can you become a living legend today? Yes! In the words of Peter Pan ““when there’s a smile in your heart, there’s no better time to start”

Want to know more about becoming a living legend?

Contact Sarah Lyon at the Alzheimer Society 902-422-7961 ext. 227 or sarah.lyon@asns.ca to request more information.



ALEXA MCDONOUGH
LIVING LEGEND

- ✓ Mother
- ✓ Grandmother
- ✓ Provincial Party Leader
- ✓ Federal Party Leader

✓ **Included a gift in her will to the Alzheimer Society of Nova Scotia**

*There's a living legend in you.
Become one today.*

U-First® Training Sessions Underway

ASNS Staff

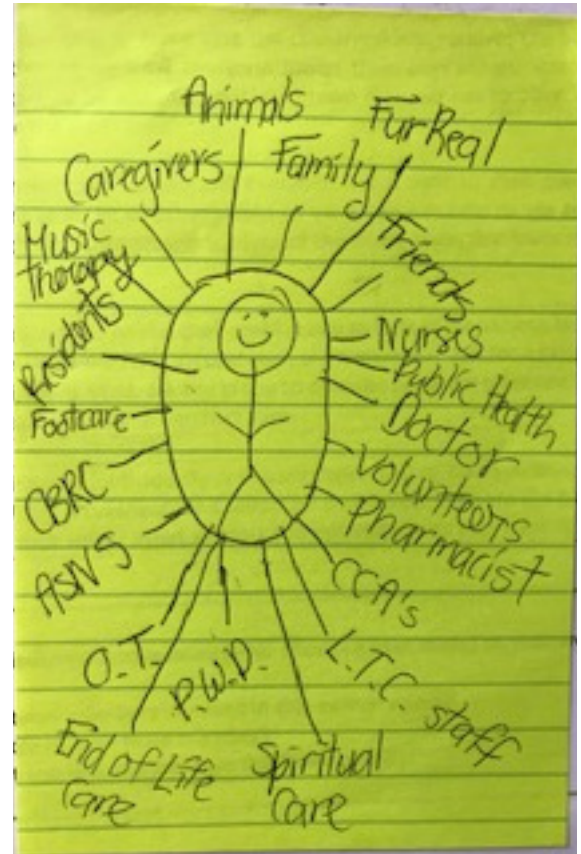
What happens when a group of health care professionals with over 160 years of experience gather in a room for the day? Great collaboration and learning! On April 26, staff from the VON and six different long-term care facilities in Pictou County participated in the latest U-First! training session.

U-First! is a six hour training program that focuses on developing a common knowledge base, language, values, and approach to caring for people with Alzheimer's disease and other dementias. This program is open to all front line staff of government-funded long-term care facilities or home support agencies in Nova Scotia. It is available at no cost to program participants or their employers because of a grant offered by the federal government.

The U-First! program is facilitated by Alzheimer Society of Nova Scotia staff and the Nova Scotia Health Authority Behaviour Resource Consultants. During the program participants recognize the important work that they do as a member of the care team, while enhancing skills and learning a framework to understand behaviour, increase knowledge about dementia, and learn which strategies might work best when providing care.

When asked what participants enjoyed most about the workshop, one participant noted they enjoyed developing strategies and working with the team to find the right solution to help each resident. Another really enjoyed how informative it was and felt the informal education style helped everyone to feel relaxed and confident to participate in interactive activities.

If you have any questions about U-First! including when the program will be offered in a community near you, please contact Heather Murdock, U-First! Training Coordinator at the Alzheimer Society of Nova Scotia at heather.murdock@asns.ca or 902-422-7961 ext. 243.



Team exercise from the U-First! session where groups brainstorm who members of the team are and list them around the person with dementia at the centre.

Make your Coffee Count Host a Coffee Break®

Serve coffee in exchange for a goodwill donation and support Nova Scotians facing the realities of dementia.



For more information or to register contact
Mark: 902-422-7961 ext. 241 or email
mark.sharkey@asns.ca



Join Team Alzheimer's
Scotiabank Charity Challenge

June 6-9, 2019

For more information or to join the
team contact Mark: 902-422-7961 ext.
241 or email mark.sharkey@asns.ca

Artful Afternoon - One Family's Experience

Kaija Whittam, Coordinator, Client Services

“Be sure to come, especially on days when the person you are caring for doesn't want to – it will magically turn both your days around.” - Hannah Minzloff daughter, filmmaker.

Artful Afternoon is a partnership program between the Art Gallery of Nova Scotia and the Alzheimer Society of Nova Scotia which has been running since the pilot in 2014. The program is for people with dementia and a partner in care, consisting of a one hour tour and a one hour artist lead art activity.



Hannah and her father at Artful Afternoon

Hannah and her father, Rainer Minzloff, have been attending the Artful Afternoon program for about two years. Rainer was diagnosed with Parkinson's disease and Lewy Body Dementia in 2015. She shares her thoughts on the program, and a bit on her new film, below.

How did life change for both of you after the diagnosis?

For all of us, particularly for Dad, it was a relief to know what the issues were and that to a certain extent medication could help to alleviate the symptoms. We learned to use tools like a white board to write down daily schedule of activities, and bit by bit, got help for Mum in the house from Continuing Care Nova Scotia. We looked for programming outside of the house to give Dad a change and stimulation, and to give Mum a much needed break from caregiving. This is how I came across the Artful Afternoon program. In October 2018, we had to move Dad to a care home because Mum could no longer manage looking after him at home.

What do you and your father each get out of the Artful Afternoon program?

The staff and volunteers have been so welcoming. My ten-year-old daughter has joined in on a couple of sessions and has also loved the experience. It has been a great way for us to connect with my Dad outside of our usual care-driven routine. Discussing and making art in response to what we see in the gallery. Seeing and talking with other caregivers and their loved ones.

My favourite memory has to be when Dad started drawing a beautiful flower on the craft paper, which my daughter and I used as a template for a felted pin. Dad gave the pin to my mother.

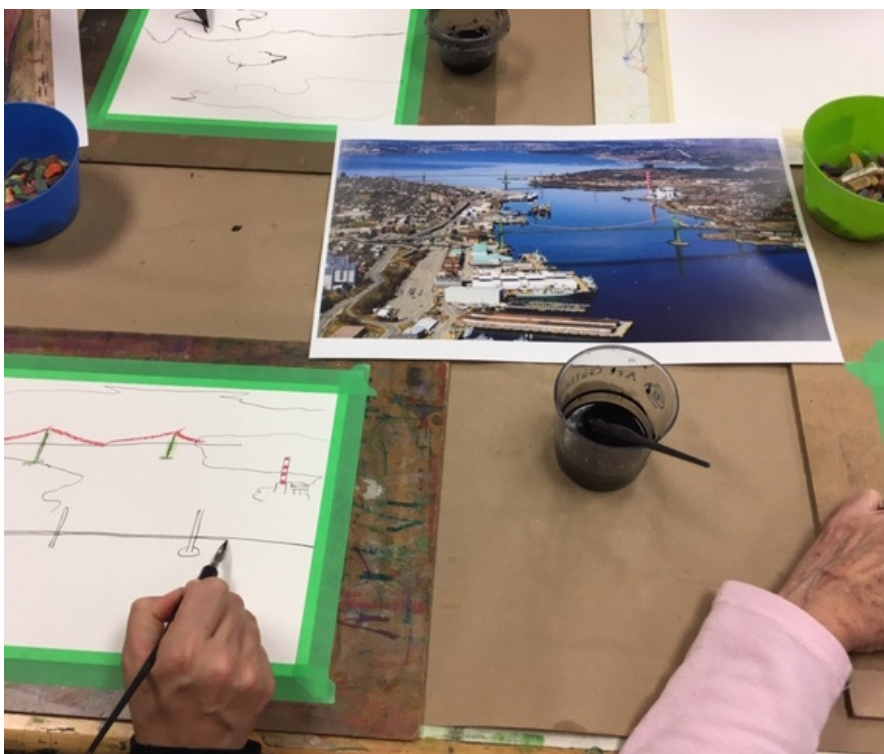
The long-lasting impact of each session has been incredible. Dad talks about aspects of what we saw, discussed, and made for months afterwards with my Mum. Be sure to come, especially on days when the person you are caring for doesn't want to – it will magically turn both your days around.

Would you tell us about the film you made about your father's dementia?

The onset of his dementia has brought a dramatic change to the relationship I have with my father. "Dementia, Dad and Me" follows the two of us as we find new ways both to connect and to navigate the delicate transition of our roles from father–daughter, to caregiver and cared for.

In making the documentary, I have filmed a couple of our sessions at Artful Afternoons. Looking back at the footage, it's amazing to see how Dad opens up to the staff and volunteers, participating a little more each session. It took two years before he began spontaneously drawing on the craft paper covering the tables! Although his health has declined significantly over the last few months, we can't wait to come back.

Thank you Hannah for sharing your thoughts with us! If you are interested in learning more about Artful Afternoon currently offered in Halifax, please call the Alzheimer Society of Nova Scotia 902-422-7961 ext. 224.



Minds in Motion® Pilot Programs

Mallory Perry, Coordinator, Client Services

This fall two, eight week pilot programs of Minds in Motion were launched based on the program offered by the Alzheimer Society of Ontario. This program included an energetic exercise class with inspirational music from Abba, the Eagles, Tina Turner, and more. Following the exercise portion, participants met for refreshments and took part in planned activities, while chatting over a cup of coffee. A participant who attended this program with his wife who lives with dementia shares their experience below.



Minds in Motion Pilot Program Session

What did you and your partner enjoy most about this program?

As this program is made up of two portions, the exercise and the social component, I will have to give two answers to this question. When it comes to the physical exercise portion of the program, it was an amazing the change over the period of weeks and the physical improvements we noticed. On the first day I (we) felt tired, but as the weeks went on, the sessions became routine and became easier even though over the weeks there was a gradual increase in the intensity of the exercise. Another aspect of this program I enjoyed were the friendships that developed, the conversations and laughs that took place, and the games we played. Participating with programs such as this, you get to understand and hear about other people's situations and how they deal with it. It is so important to talk with other people, appreciate what they are going through, and understand that there are more people involved than just yourself. It was great to be able to maintain these connections in an informal environment where we were able to participate in activities together, have fun, and carry on with our day. I feel that the deeper value of friendships was a key highlight of this program.

If someone was considering taking this program for the first time, what would you want them to know? I would make it 'a must'. Don't hold back, go and attend whatever the function is, because it is very worth-while. If you aren't sure, just give it a try and see what it is about. I've gone to many programs hosted by ASNS & I would highly recommend it. Don't make a decision until you've tried it.

When being involved in an ASNS program, there is no "push or shove", the staff are just people trying to be helpful. This is a terrific organization and the hearts of the staff are in the right place. I have to give credit to ASNS for offering these programs, being available to those who need it and for helping during this journey!

IG Wealth Management Walk for Alzheimer's

Team ASNS

Thank you for registering, raising money, sharing your photos and your stories, and for coming out across the province. A huge thank you to our title sponsor IG Wealth Management and our presenting sponsor Shannex.

On behalf of those we serve - who will have access to supports because of you - thank you.



Are You A Member? 2019-2020 Memberships Now Available

Lloyd Brown, Executive Director

In January, Nova Scotians were asked to be champions for people with dementia, in the hopes that the stigma that surrounds the disease changes. This call for action was made by people with dementia and included a new resource: A Charter of Rights for People with Dementia.

When you become a member of the Alzheimer Society of Nova Scotia, you are helping to combat stigma and raise awareness.

How? Being a member means more than just discounted benefits at our events; it means you will have the opportunity to vote at our Annual General Meeting, and this year, you will be invited to a virtual meet and greet with the new Alzheimer Society of Nova Scotia CEO. This will be a members only opportunity to have time to talk about issues that you see those on the dementia journey are having.

Your voice is important to us. I am asking you to please become a member of the Alzheimer Society of Nova Scotia today.

Other membership benefits include discounts at our annual conference (October 21 & 22) and at one of our three Awareness Breakfasts (Halifax, Sydney, South Shore).

Please fill out the membership form and return it to the Alzheimer Society of Nova Scotia by email alzheimers@asns.ca, fax 902-422-7971, or mail: 112-2719 Gladstone Street, Halifax, NS B3K 4W6.

Save the Date! Our annual general meeting will be June 26, 2019 at the Dalhousie University Club from 5:30 p.m. - 6:30 p.m. For members who cannot make it to Halifax, a link to a livestream will be sent to view online.



Sandra & Marilyn in front of the Charter of Rights for People with Dementia

Make Memories Matter with Marilyn

ASNS Staff



Marilyn thought life as she knew it was over. All she knew about dementia were negative stereotypes depicting people in their late stages of the disease.

She had been to see her doctor after noticing changes in her daily routine. She no longer felt comfortable riding her beloved bike. And if that wasn't hard enough, the doctor failed to treat her properly and instead of discussing her diagnosis, she read the word "Alzheimer's" on her prescription at the pharmacy. She hadn't even considered that as a possibility.

Marilyn fell into a dark place. The diagnosis scared her. But she wouldn't be scared for long. She refused to let her family down, or herself. As a strong independent woman she knew how to fight her way out of a tough situation.

So one day she decided enough was enough. *"There must be something out there for me. There must be help."* She did what any resourceful woman would do; she opened the phone book. That is when she found the Alzheimer Society of Nova Scotia's InfoLine. It was a call that changed her life.

"I had to remember that I love this life and I have no choice but to keep fighting. I need to be here and healthy for my family."

Marilyn takes a deep breath and looks up to the ceiling as she tries to stop herself from crying. She is remembering her first call to InfoLine. "That phone call was the beginning of a big change in my life. A good change. The Alzheimer Society opened up a new way of life for me so that I could cope and recognize my limitations. They allowed me to realize that I am a worthy person."

What would have happened to Marilyn if there was no one to answer her call? What would Marilyn's life be like today if that call had gone unanswered? We want to keep answering calls to our InfoLine. But we need your help to do that. Donate now so that we can continue helping people like Marilyn.

Société Alzheimer Society

NOVA SCOTIA

SPECIAL REPLY FROM:

Name: _____

Full Mailing Address: _____



YES! I want to help people like Marilyn! Please accept my gift of:

\$100 \$50 \$25 \$15 \$ _____

Please check your preferred payment method:

___ An enclosed cheque made payable to the Alzheimer Society of Nova Scotia

___ Please process my: ___ VISA ___ MasterCard ___ AMEX

Card # _____ Expiry: ____/____

Phone # _____ Email _____

Did Marilyn's story touch you? Would you like to send her a message?

Thank you. Please return in the enclosed envelope.
You can also make your donation at www.alzheimer.ca/ns

Hope for Tomorrow.

Thank you for supporting Nova Scotians today. Did you know that by leaving a gift in your will, to continue your legacy of giving, you can support Nova Scotians living with dementia in the future? We want to say thank you if you've made arrangements for a gift. We are also happy to answer any questions you may have.

___ I Have Made a Gift in My Will

___ I Would Like to Learn More About Making a Gift In My Will