In the Loop

SPRING 2021

Société
Alzheimer
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NOVA SCOTIA

REGISTER TODAY!

There's still time to register for, or to support, the 2021 IG Wealth Management Walk for Alzheimer's!

When you walk, you're sending a message of hope to Nova Scotians living with dementia and the thousands more who care for them.

www.walkns.ca

IG WEALTH MANAGEMENT

WALK FOR ALZHEIMER'S

Alzheimer Society

SPRING 2021

CONTENTS

Contributors

CATHERINE SHEPHERD, Coordinator, Education & Outreach, Cape Breton

CINDY DOBBELSTEYN, Volunteer

LESLEY FLEMING, Registered Horticultural Therapist, Nova Scotia Horticulture for Health Network

LINDA BIRD, Director, Programs & Services

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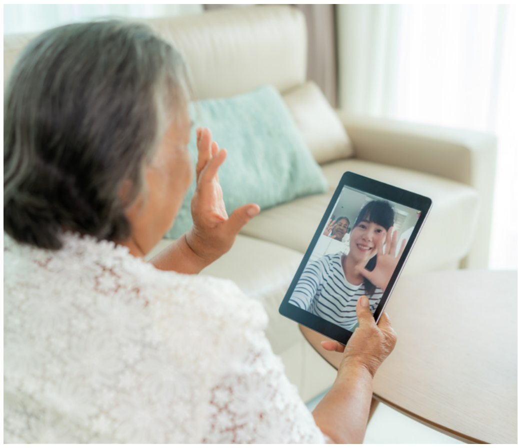
Caregiving from a Distance

Catherine Shepherd, Coordinator, Education & Outreach, Cape Breton



In today's world there are some new and unique challenges when it comes to being a care partner. Many family members live some distance from each other and with COVID-19, we are learning that being together may not always be as easy as it once was.

Taking care of a family member's safety, nutrition, finances and health can be difficult when you don't live nearby. How do you arrange help from a distance? How do you stay connected and provide care while living away?

Here are a few ideas that may help as you care from afar:

- Identify resources and use them: learn about what is available in your community by contacting your local Alzheimer Society. Call our InfoLine at 1-800-611-6345 for support.
- Reassess care needs during a phone call or video visit: dementia is a progressive disease and care will need to be adjusted over time. Check in with family members or friends who are close and ask about day-to-day care.
- Keep communication going: talk with informal support like family, friends or neighbours. Take part in the initial request for home support services by being on speaker phone. Or with permission, be part of a doctors visit over the phone or by Zoom. This will help you to know how things are going while supporting your family member.
- Keep a list of contact information for physicians or other health care practitioners, pharmacists, care providers and neighbours. Have copies of important financial and legal documents easily accessible in case they are needed.
- If your family member is living in a long-term care facility, you can always ask to speak to their managing health professional to get updates and keep the lines of communication open.
- Be kind to yourself. Living away does not mean you are not involved or that you do not care. Get support for you by connecting to a community support group or education series through your local Alzheimer Society.
- Supporting from afar can have its difficult days, whether your person with dementia is at home or in long-term care but don't underestimate the importance of supporting from a distance.

If you would like to read more about caring from a distance and other resources, visit our website at www.alzheimer.ca/ns.

1,000 Fidget Quilts - A Labour of Love

Cindy Dobbelsteyn, Volunteer

For lifelong friends Cathy Dunbar and Beth McBrine, the past three years dedicating their spare time to the making of special quilts hasn't been hard work – it's what they love to do.

The process began when Cathy discovered a website showing how to make "fidget quilts" - multi-textured lap quilts designed to provide visual and sensory stimulation for persons with dementia. Cathy initially thought about the residents who had lived with her mother in long-term care, and decided she would try to make a few by using materials she had in her home. When Beth requested one for her father with vascular dementia, Cathy told her she would have to help her make it. They had so much fun that they decided to keep on going.

Now, three years and countless hours later, "The 2 Fidgeteers" have made over 1,000 quilts which have been donated to organizations and individuals all over the continent. While most requests come from Nova Scotia, orders have been shipped as far as British Columbia, Florida and even one to the United Kingdom. Cathy and Beth have also produced and donated a large number of mini (12-inch) quilts, which are used by local RCMP and hospital staff in emergency situations to provide comfort to adults with dementia who have become lost or are in unfamiliar surroundings.

While nine of the 20 squares of each lap quilt share common aspects such as pockets, zippers, Velcro, "blue fuzzies", and a heart-themed fabric square with "Somebody Cares" labelled on it, each quilt is individualized by careful selection of colourfully patterned fabrics and additional attachments. Cathy and Beth put loving consideration of the recipient's likes, former occupation and pastimes into the quilt's design. For example, the inclusion of fabrics depicting various pets for a retired veterinarian or animal lover. Beyond occupations, additional themes include nature, travel, music, dogs, cats and sports, all which can bring back memories and provide topics for conversation. All the quilts contain a key in one pocket, which the recipients often delight in discovering. And every quilt is uniquely named; "The Cat's Meow" was designed for a cat lover. While The 2 Fidgeteers never charge for a quilt, they have gratefully received monetary and material donations from individuals and organizations, and have not incurred any personal costs since soon after the project got rolling. They have also received a lot of community support with publications in newspapers and newsletters, and opportunities to give presentations and booths at local craft fairs.

Their 500th quilt was designed to honour their dads with a numbers theme, as both had been accountants. The 1,000th they decided to do for themselves, incorporating all the things they love into the fabric choices and design: knitting, sewing, ice cream, wine, tea, makeup, nail polish, puzzles, pets and "road trips"!

Beth and Cathy say it's the heart-warming stories about the recipients that keep them going, and they cherish the tears and giggles they share while presenting or working on their projects together. They had no idea that their quilts would be so popular, and they don't plan to stop making them until they stop having fun.

JOIN US ON THURSDAYS FOR ONLINE EDUCATION!

ALZEducate

- Various topics & presenters
- Information and conversations about Alzheimer's disease and other dementias
- Open to anyone at no cost, just register online!

Sessions are held via ZOOM every second Thursday from 1:30-2:30 p.m.
For more information visit alzheimer.ca/ns

Connect with the Outdoors - A Healthy Strategy

Lesley Fleming, Registered Horticultural Therapist
Nova Scotia Horticulture for Health Network

Why not have fun doing healthy activities! Connecting with nature and being outdoors is a health strategy important for everyone, with lots of options that can provide joyous moments. Research shows that improved cognitive ability, mood, social connections and stress reduction are related to time outdoors. For people living with dementia, the benefits of connecting with nature can address health challenges including reducing agitation and late day restlessness, increasing melatonin production which impacts mood, providing physical activity, sensory and intellectual stimulation.

Outdoor activities don't have to be difficult! Consider some of the following ideas:

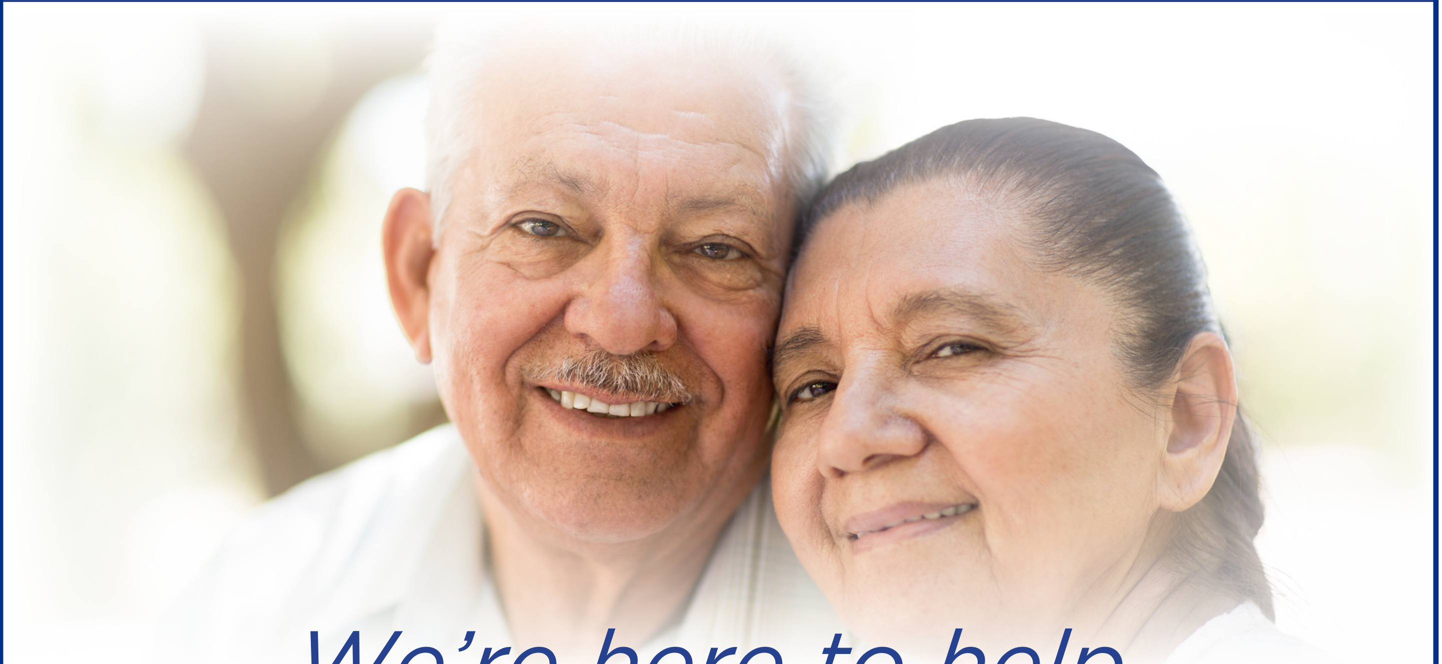
- Walking in gardens, forests or even neighbourhoods – get physical exercise with your care partner or family while enjoying flowers in bloom, birds singing, and the colors of nature. This can add a nature dimension to your routine, breaking up the day with fresh air and a healthy activity.
- Plant flowers, shrubs or food – what have you or your loved one planted in the past that you were passionate about? Consider doing a small gardening project like a container garden where the activity is less about talking, more about hands-on doing. Choose non-toxic plants like geraniums, pansies, pentas or herbs, and empower decision-making when the selection of container, plants and colors are done by the person living with dementia.
- Join a community garden – this can provide a social outlet, a physical activity, and a chance to grow and eat healthy food. Participating with care partners or family can rekindle interest in fun outings and positive time together. Become part of the larger community in a setting where nurturing is second nature.
- Plant crafts – be creative indoors or outdoors. Trace leaves, paint flowers, do a flower arrangement. Or make a flower halo, daisy chain or pressed flower notecards. Supervise tools and choose non-toxic materials. Make an extra one to give away.

Participating in nature-focused activities can provide joy, beauty, meaningful experiences, and in the moment sensory stimulation for everyone. For people living with dementia, these activities can offer opportunities to work collaboratively

with others, communicate without lots of verbal exchanges, and find satisfaction in completing a project, with a focus on abilities not deficits. Simply smelling the roses counts as a health booster too!

Lesley Fleming, HTR has worked with people living with dementia for more than a decade, delivering therapeutic horticulture in a variety of settings. Previously published works include: Art Museums Offering Programs for People Living with Dementia and Their Care Partners (2021), A 2020 Update on People-Plant Programming with Dementia Populations, and her ebook Therapeutic Horticulture A Practitioner's Perspective (2016). Her April 2021 webinar on this topic is available on our website at www.alzheimer.ca/ns/virtual-education.

Alzheimer InfoLine | 1-800-611-6345



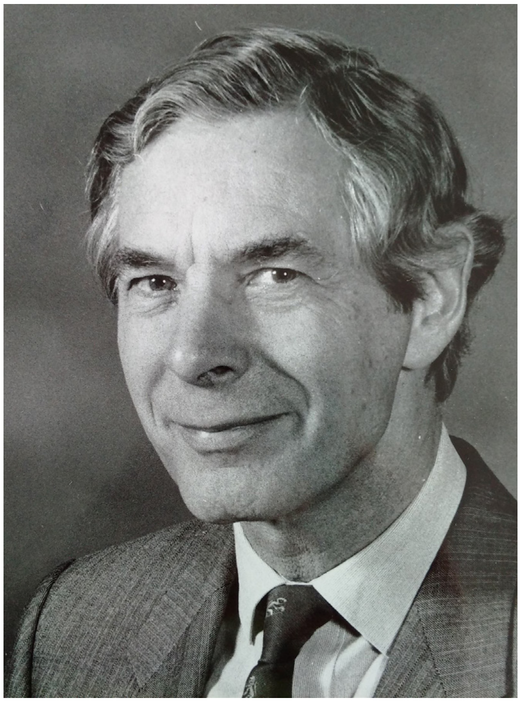
We're here to help

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.

The Legacy of Dr. John Gray

Linda Bird, Director, Programs & Services



On February 16, 2021, we said goodbye to a true pioneer. Dr. John Gray was a leader of Alzheimer and dementia care in Nova Scotia and beyond, and one of the founding members of the Alzheimer Society of Nova Scotia (ASNS).

Dr. Gray was born in England. After medical school, he spent 25 years with the International Grenfell Association in Newfoundland and Labrador. This organization was devoted to serving isolated and underserviced people of the region. Dr. Gray made house calls by boat and dog sled! (A few years ago, Dr. Kenneth Rockwood, geriatrician, had the foresight to document Dr. Gray's remarkable history in a video called *This is John Gray*, which you can watch on YouTube at www.youtube.com/watch?v=o0Q9CTzZ1Mk).

In 1981, Dr. Gray was asked to come to Halifax to lead the development of a new Division of Geriatric Medicine at Camp Hill Hospital. After a year of advanced training in geriatric medicine in England, Dr. Gray began his work in Halifax establishing what we now know as the Geriatric Ambulatory Care Memory Clinic. His fine portrait graces the clinic's walls.

In 1982, not long in his new role, Dr. Gray was approached by Phyllis Horton and Constance Baird, both caregivers of a family member, asking for his help to make it easier for family caregivers to access information and support on Alzheimer's disease, here in Nova Scotia. This led to a public meeting at Bethany United Church where it was decided to establish a provincial organization. Dr. Gray, Dr. Nigel Allison, and Dr. Stephen Bedwell were all early providers of education on dementia and support of caregivers.

Kevin Keefe saw a poster advertising an Alzheimer information session at Oxford School. Having lost his mother the year before, Kevin attended the meeting to contribute something from his experience as a caregiver. He walked out as the new president, and looking the part as he was the only one present wearing a shirt and tie. Besides Kevin's invaluable experience providing care to his mother, he was skilled with start-up business ventures, a perfect combination as the first president. In 1983, Kevin filed the papers to have the Alzheimer Society of Nova Scotia registered under the Societies Act.

With the society established, volunteers, and then staff as the Society grew, started to build the foundational pieces to support caregivers in making the dementia journey better; public awareness, information, education, support and advocacy. Dr. Gray's hand and philosophy of care continued to guide the work of the Society through those early years and into the present.

An early volunteer with ASNS, Anne Hallisey reflects, "Dr. Gray was always a gentleman." A sentiment that is echoed by all who encountered him. Anne remembers in the early days that Dr. Gray was active with the newly established programs and you could always count on him – "People were desperate for information," she says. Dr. Gray spoke at the family support groups and the annual symposiums on Alzheimer's disease hosted by ASNS.

"That early group of ASNS volunteers were fierce and devoted to making a difference for families," says Anne.

In addition to sharing his knowledge and organizational skills, Dr. Gray and his wife Fiona also supported essential fundraising for the Society. They produced postcards depicting our beloved South Shore that were sold in local shops to help raise much needed funds.

Over my own seventeen years with ASNS, I have had the pleasure of speaking with Dr. Gray many times. He was always genuinely interested in how the Society was doing, how our programming was evolving, and was always concerned about the welfare of caregivers and the individuals they were caring for.

Dr. Gray will be remembered in many ways. As a mentor, educator, doctor and advocate. We are immensely proud to say that part of his legacy is his role in establishing the Alzheimer Society of Nova Scotia. Through his leadership, vision, mentoring and actions, he set standards for person-centred care that are still at the heart of the work we do today. We are committed to carrying on his legacy and are in the beginning stages of a new project to support people on their journey with dementia. Dr. Gray's work will not be forgotten.

READER SURVEY

Thank you to everyone who took the time to fill out and return the reader survey that was included in the winter 2021 issue of In the Loop. Your feedback will help us continue to improve our newsletter and help us better connect you to the things you want to see.

A winner was selected for our gift card draw and was contacted directly!

How do we Talk About Capacity & Dementia?

Catherine Shepherd, Coordinator, Education & Outreach, Cape Breton

Originally published in the Cape Breton Post

Capacity. It's a topic that raises lots of questions. A couple months ago, the Society hosted an online public presentation with guest speaker, Raylene MacDonald, who is a retired geriatric psychiatry nurse with a wealth of knowledge on this topic. Raylene, a native Cape Bretoner from Westmount was the first nurse to become a designated capacity assessor under the Adult Capacity and Decision Making Act (ACDMA) in Nova Scotia. We're so thankful she shared her knowledge with us, and I'd like to share some of her insights with you.

Many families I talk with have questions about what capacity is and how it is assessed. Capacity is the ability to understand information relevant to a decision and to appreciate the consequences of the decision. Capacity is a fundamental human right to make your own decisions. People have a right to consent, refuse, or withdraw their consent to care and treatment and to manage their own affairs.

Being older does not mean that you lack capacity. A diagnosis of dementia does not necessarily mean you lack capacity. Capacity is complex and will change with the progression of dementia. It is often difficult to know when someone's capacity to make decisions changes and support is needed.

"If a person is making unwise decisions it doesn't mean that a person lacks capacity because a person with capacity has the freedom to make unwise decisions," says Raylene. "Capacity is not black and white. If you lack capacity in one area, it doesn't mean you lack capacity in another area. For example: maybe someone is having cognitive changes and difficulty managing finances. They might lack capacity for financial decisions, but still retain capacity for personal care decisions."

Another question people often ask is who is qualified to assess capacity. In Nova Scotia, it is legal for physicians, psychologists or a designated capacity assessor listed on the Public Trustees website to assess capacity.

Raylene MacDonald

“When doing a capacity assessment, you’re really taking information in from a whole variety of sources,” says Raylene. “The interview with the person is the gold standard for sure, but you’re also looking at the person’s medical history, and you’re talking to people who have known this person in the past. Family of course, and anybody with a history like the family doctor. I’ve gotten invaluable information from the pharmacist and home care staff who would see the person daily.”

Those who assess capacity don’t take it lightly. It’s always assumed that any adult has capacity until it is deemed otherwise. People are only declared incapable when it has been firmly established that they lack the ability to make decisions or are at serious risk because of their incapacity.

“We know that those living with dementia have good days and bad days and good times of the day and other times that aren’t so good,” says Raylene. “That person’s capacity fluctuates in the run of a day and they have the right to choose to have a capacity assessment at their optimal time of day. If capacity is fluctuating for whatever reason, the person may need to have it reassessed several times.”

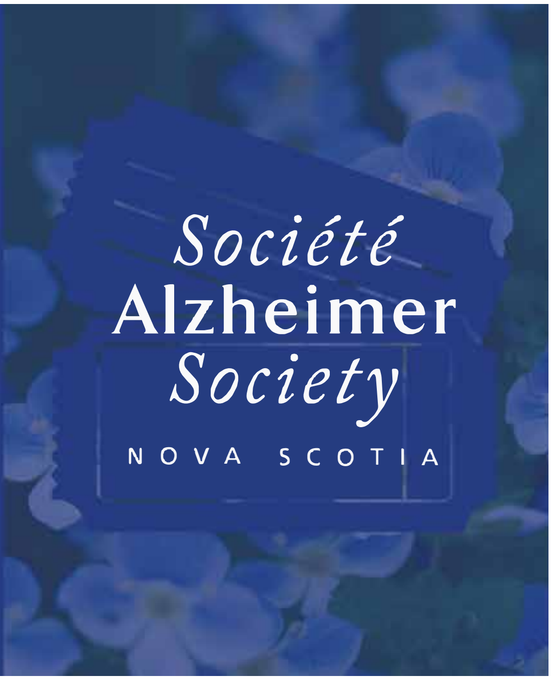
The right to make decisions affecting our daily lives is important to all of us. We need to include people in the discussions and decisions, to the best of their abilities.

If you have more questions about capacity or any other dementia related topic, please reach out to the Alzheimer InfoLine at 1-800-611-6345. To watch Raylene’s presentation on capacity, please visit the our YouTube channel: www.youtube.com/alzheimerns.

SPRING INTO ACTION
50/50 JACKPOT RAFFLE!

Get your tickets by May 30 to help support over 17,000 Nova Scotians living with dementia and get a chance at half the jackpot!

www.rafflebox.ca/raffle/asnsraffle



Not About Us Without Us

Sacha Nadeau, First Link® Outreach Coordinator & Research Liaison

"With COVID-19 there is so much I can't do, this is one thing I can do to make a difference," reflected Marilyn Taylor, who lives with dementia and is one of the newest members on a research team in Nova Scotia.

The pandemic has sparked many questions about our healthcare system, how it is accessed and the potential behind virtual care. One research team in Nova Scotia is exploring these questions and how they relate to dementia care.

They are building a province-wide survey on the current needs of people with dementia including diagnosis, treatment, clinical care and community support. Beyond this, they will explore attitudes toward Telehealth, accessing health care services remotely by phone or internet, and whether it can help address any gaps.

Dr. Paula McLaughlin leads the project, "Identifying, Understanding, and Mitigating Gaps in Dementia Care in Nova Scotia." She is the recipient of Research Nova Scotia's New Investigator award and a QEII Foundation Translating Research into Care (TRIC) Health Care Improvement Program grant.

Her research team includes geriatricians, psychologists, neuropsychologists, health services researchers, a statistician and an Alzheimer Society staff member. Since August of 2020, they have been ironing out project details and recruiting one important missing perspective.

Who better to identify the most important gaps in dementia care than the people experiencing them?

Welcome Marilyn Taylor and Sandra Britten, recent additions to the team who are bringing their dementia lens to the survey development. Marilyn and Sandra are no strangers to committees amplifying the experiences of people with dementia. In one meeting alone, they have clarified instructions, improved formatting, and shared personal care experiences to ensure the research team asks the right questions in the best way.

"Marilyn and Sandra are a welcome addition to our team and are essential to the

Sandra Britten

Marilyn Taylor

success of this project," says Dr. McLaughlin Researchers and clinicians can miss the mark on what is important. They will help ensure that our research is relevant and meaningful."

Including the voices of persons with dementia and their caregivers as advisors, not just participants, is a critical shift in the research world. Engagement is at the heart of what we do at the Alzheimer Society of Nova Scotia. We take great care in facilitating linkages between research teams and persons with lived experience by mapping out participation preferences and ensuring they are supported throughout the experience.

Are you part of a workplace committee or research team looking to include the voice of someone with lived experience? If so, we recommend accessing the resource guide with practical tips for meaningful engagement at www.bit.ly/asnsresourceguide. It was developed by the Alzheimer Society of Canada, in collaboration with, you guessed it, persons with dementia!

Current Research Opportunities

Below is a list of projects that are currently seeking research participants. Note that all projects have been approved by our knowledgeable Research Advisory Board who ensure they are appropriate and meet ethical standards.

Project Title	**Lead researcher**
"Can automated cars help people with dementia drive longer?"	Mohamud Hodan
"From Hospital to Home for Persons Living with Dementia: A Multi-Perspective Qualitative Study"	Marianna Saragosa
"Perceptions of the Caregiving Role Among Young-Onset Dementia Adult Child Caregivers"	Camryn Berry
"Feasibility and Preliminary Effectiveness of Namaste Care Delivered by Caregivers of Community-Dwelling Older Adults with Moderate and Advanced Dementia: A Mixed Methods Study"	Marie-Lee Yous
"Evidence to Assess the Impact of COVID-19 on Community-Based Dementia Care in Nova Scotia"	Dr. Katie Aubrecht
"From the inside out: The integration, optimization, and promotion of inclusive approaches to supporting LGBTQI2S PLWD and their unpaid primary carers"	Dr. Samir Sinha
Dementia Journey Survey – A survey to help to understand the experiences of culturally diverse seniors and their caregivers when they visit their family doctors for their dementia-related needs.	Drs. Saskia Sivananthan & Sid Feldman
"Community Based Navigation Programs in Canada"	Drs. Robyn Urquhart & Grace Warner

To learn how to participate, visit www.alzheimer.ca/researchopportunities or contact Sacha at sacha.nadeau@asns.ca or 902-229-5954.

Dear Friend,

As Coordinator for Education, Support, and Outreach at the Alzheimer Society of Nova Scotia, and part of the toll-free Alzheimer InfoLine team, my phone rings a lot.

Since the pandemic struck, it rings a staggering 20 percent more.

The people who call me are spouses, parents, grandparents, children, grandchildren, nieces, nephews, friends, and neighbours. Their voices are panicked, tired, frustrated, and confused – even more so than usual.

Simply put, the pandemic is a caregiver's nightmare.

But, just as demand for our programs and services surged, COVID-19 made our fundraising efforts more challenging than ever!

My friend, I know you have been a valued supporter of the Alzheimer Society of Nova Scotia in the past. Your support has not gone unnoticed. That's why I'm hopeful you'll help again right now.

Please, won't you consider rushing the Alzheimer Society of Nova Scotia an urgent, tax-deductible donation to ensure we're able to continue helping those who need it the most?

Your generous gift will ensure that I'll be able to pick up the phone, dial out, and say...

"It's Beth from the Alzheimer Society of Nova Scotia. I got your message and I'm calling to say yes, we can help."

Thank you for your continued support of the Alzheimer Society of Nova Scotia. None of our life-changing work would be possible without you.

Sincerely,

B House

Beth House,
Alzheimer Society of Nova Scotia

Société Alzheimer *Society*
NOVA SCOTIA

Contribution Reply Form

Name: ________________________________

Full mailing address: ____

____

Yes! You can count on me to help ensure that caregivers, family members, and those living with dementia get the support they need.

I understand that this year's IG Wealth Management Walk for Alzheimer's is unlikely to raise as much as prior years due to COVID-19 and I know the demand for ASNS programs and services is on the rise due to the pandemic. To help, I'd like to make a one-time tax-deductible contribution of:

☐ $20 ☐ $50 ☐ $100 ☐ $ ___________

OR

I would like to support the Alzheimer Society of Nova Scotia with a monthly gift of:

☐ $10 ☐ $20 ☐ $50 ☐ $ ___________

You can stop your monthly gift at anytime by contacting Alzheimer Society Nova Scotia by phone or email.

PAYMENT INFORMATION:

☐ Please charge my donation to my:

☐ Visa ☐ MasterCard ☐ AMEX

Cardholder name: ___________________________________

Card number: ______________________________________

Expiry: ___/___ CVC: _____

Cardholder signature: ________________________________

OR

☐ I have enclosed a cheque payable to the Alzheimer Soceity of Nova Scotia

Thank you! Please return to 112-2719 Gladstone St, Halifax, Nova Scotia B3K 4W6. You can also make your secure donation at **www.alzheimer.ca/ns/donate.**

Would you like to leave a message for ASNS? _________________________________

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May we share your message with others? ☐ Yes ☐ No

In the Loop

SPRING 2021

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

No one should face dementia alone.

Read how you make that possible in our latest newsletter.

Forget Me Not
Ne m'oubliez pas