

In the LOOP

FALL 2024

Société
Alzheimer
Society

NOVA SCOTIA



In this issue:

- Dementia and Indigenous Peoples
- Advocacy in Action
- The Dignity of Risk

...and more!

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Questions about
dementia?
We are here to help.

Our province-wide Dementia
Helpline is a confidential
service provided by our team of
knowledgeable and caring staff.

Dementia Helpline
1-800-611-6345

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Message from John Britton, CEO

Fall is our busiest season each year, and we're already well underway just a few weeks in! This fall is going to be a very educational one here at the Society.

We're just coming off the heels of our second annual Community Week – an incredible expansion of our previous Community Night – bringing educational events to communities across the province. From Digby to Sydney, we held SEVEN events where people could learn about resources available to them, right where they live. Read more about it on page 6.

Our annual provincial conference is only a couple weeks away on October 22, marking its 35th year! I always look forward to seeing the dementia care sector in Nova Scotia come together for this day of learning and sharing. Giving voice to underrecognized elements of dementia care this year will give us all a lot to learn. Learn more and see the full conference program on pages 8-9.

With municipal elections happening across the province on October 19, it's the perfect time to help educate your newly elected Council officials on how they can support making our communities more Dementia Friendly. Learn more about Dementia Friendly Communities, including some questions you can ask your local Councillor, on pages 10-11.

As we move through our busy fall season, and soon onto the winter holidays, we'll have many more educational opportunities for you. I encourage you to check out our website at www.alzheimer.ca/ns or call us at 1-800-611-6345 to see what's available!

Thank you, as always, for staying 'In the Loop' on what is happening at the Society and for supporting us as we provide help for today and hope for tomorrow to the thousands of Nova Scotians affected by dementia – and the many thousands more who care for and support them.



A handwritten signature in blue ink, appearing to read 'John Britton', with a long, sweeping underline.

John Britton
CEO, Alzheimer Society of Nova Scotia



We would love to hear your feedback! Send us an email at alzheimer@asns.ca.

The Many Faces of Dementia in Canada: Dementia and Indigenous Peoples

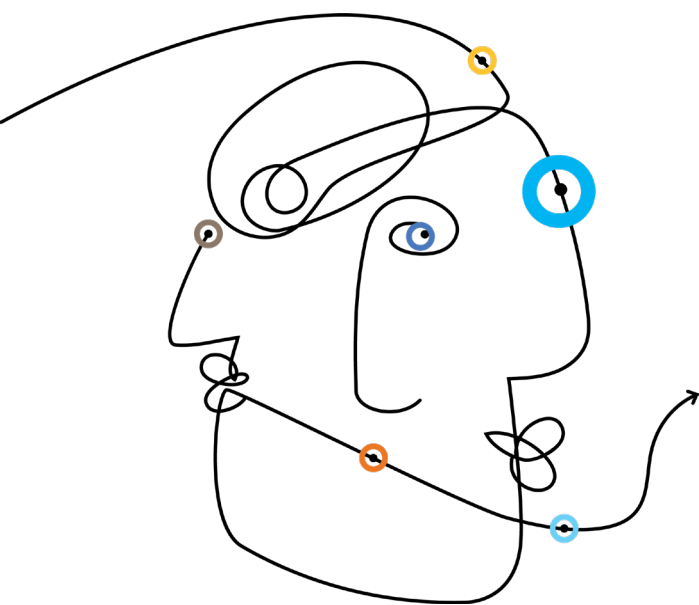
In January, the Alzheimer Society of Canada released the second volume of the Landmark Study, *The Many Faces of Dementia in Canada*.

Over the past few months, we've been doing a deeper dive on each chapter through online education pages sharing more about this study, what it means for Nova Scotians, and what resources are available to help.

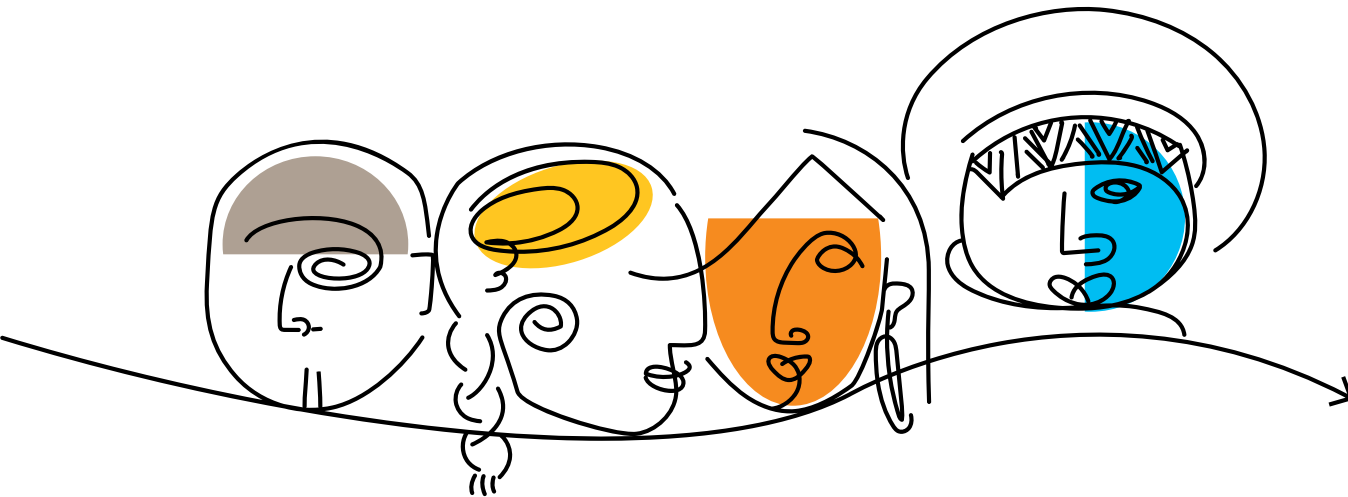
It's important to share local statistics and resources, and to hear from Nova Scotians about ways in which their cultures and social identities are related to their experience on the dementia journey.

In recognition of Truth & Reconciliation Day last month, we're talking about Chapter 2, *Dementia and Indigenous Peoples*. This chapter confirms that dementia is a growing public health issue for Indigenous Peoples in Canada. Research indicates higher rates of dementia among Indigenous populations when compared to the general public. Indigenous Peoples also face challenges accessing health-care services and receiving supports.

**Read this chapter online at
alzheimer.ca/ns/manyfaces-chapter2**



Colonialism is a root factor of dementia risk and other health problems in Indigenous populations. Risk factors for dementia are also strongly impacted by social determinants of health; the resulting stress and racism affect both brain health and access to health care. An Indigenous determinants of health model clarifies the interconnection between health and social factors. The model looks at systems, and the complex web of associations between individual and social factors that exist for the health of all people.



**You can see all these
education pages online at
alzheimer.ca/ns/landmark2**

The Report calls for Indigenous-centred and Indigenous-led research, and culturally safe dementia resources and health care services. This chapter includes a graphic mapping the problem of Indigenous-specific racism in healthcare and suggests ways to break the cycle. It closes with the stories of Inuit, First Nations and Métis resilience in the face of dementia.

“Startling increases of dementia amongst Indigenous peoples and the multi-facet reasons as to why are outlined in Landmark 2,” says Vanessa Nevin, Director of Health, Atlantic Policy Congress of First Nations Chiefs Secretariat. “Indigenous people living with dementia and their families need supports and services that are grounded in culture, language, and access to our traditional foods, while also seeking medical model treatments that understand our distinct needs.”

We have many resources connected to this Chapter and specific to the Indigenous experience of dementia. You can find them online at alzheimer.ca/ns/manyfaces-chapter2 or by calling our Dementia Helpline at 1-800-611-6345.

If you see yourself in this report, or are a community organization or healthcare provider and have suggestions on how we can better support you and your community, we invite you to contact us by email at alzheimer@asns.ca or phone at 1-800-611-6345.

Community Week 2024: Supporting People Affected by Dementia Where They Live, Work and Play

Our second annual Community Week was a resounding success! We couldn't have done this without community support across the province. Thank you to everyone who participated and showed up to learn about ways to support people affected by dementia, whether a care partner or someone living with dementia.

With over 300 participants attending seven events across the province, it is clear that our communities want to make their spaces dementia friendly. These events featured presentations from individuals living with dementia and care partners, as well as local professionals from services and organizations including Senior Safety Coordinators, Behaviour Resource Consultants, Recreation, and more.



Celebrating 17 Years with ASNS: Denise Fitzgerald



Our longest standing staff member, Denise Fitzgerald, just recently celebrated her 17th anniversary with the Society. When Denise started with us as a work-term student in 2007, we had just 10 staff. She was hired full-time after her placement on our reception desk, and she's been here to see the organization grow to over 40 staff.

Over the years as we've grown, moved offices and changed, Denise has held a few different positions with different responsibilities. Today, she is our Donor Relations Coordinator. If you've received a tax receipt or a thank you letter from us, it's her behind the scenes coordinating.

Inspired by the donors she works with every day, Denise became a donor as well. She shared that she donates each month because she's seen firsthand how the Society has grown and the impact that we've had. From a completely volunteer run Helpline 17 years ago, to a professional staff with over 4,000 support calls per year.

"I give monthly because I want to be part of helping people with dementia," says Denise.

"I see myself every day how the dollars raised makes a real impact on people through our programs and services. I've loved seeing the growth of the Society over the years and I can clearly see how we're going to continue to grow."

If you'd like become a monthly donor yourself, visit alzheimer.ca/ns/donate or call us at 1-800-611-6345.

GIVING TUESDAY

Save the Date - We're participating in GivingTuesday on December 3rd!

Giving Tuesday is a time when Canadians, charities, and businesses come together to celebrate giving and participate in activities that support charities and non-profits; to thank, help, give, show kindness, and share what they have with those in need.

Exploring Unseen Dimensions of Dementia Care



We're thrilled to be hosting our 35th Annual Conference, Exploring Unseen Dimensions of Dementia Care! Join us on Tuesday, October 22, 2024.

Our conference offers a prime opportunity to explore care practices and build new connections to strengthen the dementia care sector. Gather with us in person at the Delta Hotel in Dartmouth, or join our virtual livestream.

Exploring Unseen Dimensions of Dementia Care

This year, we'll explore underrecognized elements of dementia care. We'll open with a conversation about culturally appropriate care for our diverse communities in Nova Scotia. Throughout the day, we'll equip attendees with new tools for everyday necessities like oral health, communication and mobility. We'll discuss MAiD and end-of-life, examine going missing, and hear firsthand about spousal caregiving.

2024 Conference Program

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35th Annual Conference

Exploring Unseen Dimensions of Dementia Care

7:45 AM Doors Open

8:30 AM Opening Remarks
The Honourable Barbara Adams, Minister of Seniors and Long-Term Care

8:45 AM Fireside Chat: How Can We Best Support the Many Faces of Dementia?
Sylvia Colley Ewing, Northwood, Caregiver
Meagan Peters, VON
Priscila Campos, Immigrant Services Association of Nova Scotia
Lana MacLean, North End Community Health Centre, Caregiver

10:00 AM Break

10:20 AM Mouth Matters: Addressing Oral Health, Eating and Communication in Dementia Care
Dr. Rebecca H. Affoo, Dalhousie School of Communication Sciences & Disorders
Dr. Ellen Hickey, Dalhousie School of Communication Sciences & Disorders
Shauna Hachey, Dalhousie School of Dental Hygiene

11:20 AM The Multiple Dimensions of Going Missing Among Persons Living with Dementia
Dr. Lili Liu, University of Waterloo Faculty of Health

12:10 PM Lunch & Exhibits
12:50 PM - Meet the ASNS Student Research Award Recipients

1:00 PM Dementia Moves: Developing an Individualized Group Exercise Program for Long-Term Care Residents with Advanced Dementia
Dr. Caitlin McArthur, Dalhousie School of Physiotherapy

1:50 PM End-of-Life Care and MAID: Compassionate Approaches for People with Dementia and Caregivers
Louisa Horne, Epilog Transition Services

2:50 PM Movement Break with Cia Tweel, Cia's Body Works

3:10 PM Promising Practices Showcase - Presented by Shannex
Mary MacLean-Bent, Away for the Day Adult Day Program
Reanne Evans & Shaureen Shephard, Tideview Terrace
Jane Kelderman, Maritime Oddfellows Home

4:00 PM Choosing Meow Meow in Spousal Caregiving: Keeping Things Simple to Make the Journey Smoother
John van Gurp ft. video appearance by musician Terry Kelly

4:15 PM Prizes & Closing Remarks

Advocacy in Action

Rosanne Burke

Manager of Advocacy

Municipal elections will be held on October 19, 2024. You can help make your newly elected Council officials aware of the need for your community to be Dementia Friendly.

What is a Dementia Friendly Community?

Dementia Friendly Communities support, respect and include people living with dementia and their partners in care in the places they live, work and play. They are communities that enables contribution, opportunity and choice.

Why is Becoming Dementia Friendly Important?

Municipal governments are primarily responsible for decision-making around vital services and infrastructure such as public transit, parks, recreation, cultural programs, libraries, community planning and emergency services. When municipalities consider people living with dementia and their care partners in policies that affect their everyday lives, it ensures people can age in place and remain engaged members of their communities.

Did you know?

Dementia friendly principles, both social and physical, make spaces more inclusive, supportive and accessible for everybody! Municipalities can lead the way for businesses and organizations to recognize, respect and respond to the needs of people affected by dementia.

Most importantly, municipal officials want to hear from their constituents to let them know why a Dementia Friendly community is important to you. Already see signs of Dementia Friendly initiatives? Be sure to point out the positive examples and the difference they make.



Three Questions to Ask Your Councillor:

1. Will you support the inclusion of Dementia Friendly principles in the development of your community's accessibility plan?
2. Given the increased frequency of powerful storms in the province, will you support dementia education for First Responders to help keep people living with dementia safe in our community?
3. When designing policies, programs and services, will you consult a range of voices of people with lived experience who may be affected?

Wondering who your Councillor is? Check your municipality's website for information on your local Council members and how to contact them.

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Advisory Committee of People Living with Dementia



We're inviting people living with dementia from across Nova Scotia to join our Advisory Committee of Lived Experience.

This committee will ensure that the voices of those living with dementia are included in all aspects of our organization, from strategic direction to program planning.

The goal is to be informed by a range of perspectives including those from diverse and equity deserving communities.

In addition to the Committee, there are other opportunities to share your voice and expertise:

- One-on-one meetings with the Manager of Advocacy
- Occasional small group meetings
- Bi-annual town hall meetings
- Projects depending on your interests, skills, and time

**Interested? Please contact Rosanne Burke, Manager of Advocacy
Rosanne.burke@asns.ca or (782) 446-3215**

The Dignity of Risk

What is the Dignity of Risk?

The Dignity of Risk is being able to express your autonomy in your day-to-day decisions and life, in a way that recognizes there may be risks associated with how we live the life we choose. Risk is a part of life and maintaining a high quality of life in the context of ageing and frailty requires us to bear the risks that come with striving to maintain autonomy.

Dignity of Risk means that despite living with disabilities related to frailty and ageing, a person should still be supported to take reasonable risks in their lives that reflect their individual preferences, dignity, and values. The freedom to take meaningful risks and exercise choice with varying consequences is part of what makes us human as we learn, explore and adapt, throughout the entirety of life's journey.

Why is the Dignity of Risk important to people living with dementia?

People living with dementia may experience several disabilities including difficulties with memory, language, problem solving, judgment, orientation, spatial awareness, and lack of insight into their needs. These disabilities will affect the person's social relationships and daily activities. As a result, many day-to-day risks will arise with dementia progression, such as risks with taking medications, planning and making meals, orienting home while going for walks or outings, and eventually risks associated with toileting, bathing, falls, and walking.

The Dignity of Risk acknowledges that living with dementia will come with risks, however it is important to balance support and strategies for these risks with the person's autonomy, self-determination, and right to take reasonable risks in their life, as a human with values and personhood.

Knowing how to identify and anticipate risks as the disease progresses can help prepare them and their partners in care to plan to mitigate risks, while maintaining dignity and autonomy within their daily lives. Often the default is still to "protect and keep safe," as well as remove independence and choice from people living with dementia, in a restrictive way that reduces their autonomy and dignity of risk.

**"There can be such a thing as human dignity in risk,
and there can be a dehumanizing indignity in safety."**

- Perske, 1972

There are barriers that many experience to adopting a Dignity of Risk approach. These can include:

- **Ageism** – believing an older adult can't or shouldn't do something based on their age. Ageism can be internalized by older adults themselves, leading them to think they can't or shouldn't do certain things.
- **Paternalistic attitudes** – when we insist that older adults need to be protected, kept safe, or watched so that nothing "bad" can happen to them. When an overly restrictive approach is used to help someone with dementia to avoid all potential harm, it's often at the expense of that person's wishes, dignity, and right to risk.
- **Overfocus on safety** – black and white thinking about whether someone or an activity is safe or unsafe. This may remove autonomy too early or unnecessarily, rather than understanding how to identify and lower risks where possible.
- **Our own personal values regarding risk in life** – how risk avoidant or risk tolerant we are as individuals, based on our own lived experiences. We may be negatively impacting people living with dementia with these personal values.

A Dignity of Risk approach can be integrated into day-to-day life. Instead of avoiding the risky activity altogether, we can lower risk while the person still enjoys the activity by utilizing some available resources. **Some examples include:**

- GPS location technology, brightly coloured clothing or having a support person accompany can help to lower risk when walking or spending time outdoors
- Using a mobility aid or a support person can help someone continue to walk, even though they may be unsteady
- Stove sensors and monitors can allow someone to continue to cook for themselves while lowering the risk of leaving the stove on

Note: If a strong risk to others has been identified, it may not be as realistic to uphold the dignity of risk approach. However, identifying and reducing risks where possible can still aim to support the person living with dementia while reducing risks for others.

Want to learn more about the Dignity of Risk? Contact the Dignity of Risk team with the Frailty and Elder Care Network. Email: dignityofrisk@nshealth.ca

Additional resources:

- Nothing Ventured Nothing Gained: Risk guidance for people with dementia
- Dementia Helpline: 1-800-611-6345.

Your Support is Crucial Right Now

Dear Reader,

As a researcher and Master of Science student at Dalhousie University's Department of Medical Neuroscience, I've seen the transformative power of support of people like you firsthand.

Your support for the Alzheimer Society of Nova Scotia funds essential programs and services, and groundbreaking research. It was thanks to donors like you that I was awarded the Phyllis Horton Graduate/Postdoctoral Research Award, which validated my work and enabled me to continue my research!

But with funding getting harder to come by – and with exciting advancements in neuroscience breathing new life into the work I do in the lab – your continued support is crucial right now.

That's why, on behalf of the next generation of researchers and every family affected by dementia, I'm asking you to support the Alzheimer Society of Nova Scotia with a new donation of whatever you can spare.

This is personal for me. As a child, I witnessed dementia firsthand with my great-grandparents. I loved them so much and cherished the fun we had together, but I was so hurt and perplexed when they could no longer play with me – or even remember me...

No child should ever have to experience that pain and confusion. But, thanks to you, hope is on the horizon.

The future of neuroscience research is accelerating exponentially, and while good science takes time, I am hopeful that our research is progressing towards new treatments to improve quality of life.

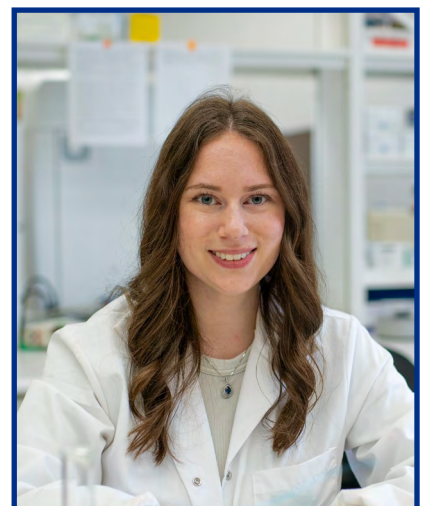
So please, can I count on you to build on the progress you've made possible by supporting the Alzheimer Society of Nova Scotia with a new gift today using the reply form on the following page?

Thank you for having such a profound impact. Your generosity has unlocked a renewed sense of hope and optimism for all of us.

Sincerely,



Gabrielle Hanson



2024 Phyllis Horton Graduate/Postdoctoral Research Award Recipient

Make a Donation

You can also make your secure donation at www.alzheimer.ca/ns/donate or by filling out the form below.

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 would like to support the Alzheimer Society of Nova Scotia with a **one time** gift 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 us by phone or email.

PAYMENT INFORMATION:

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

OR

☐ Please charge my donation to my: ☐ Visa ☐ MasterCard ☐ AMEX

Cardholder name: _____

Card number: _____

Expiry: ____/____ CVC: _____

Cardholder signature: _____

☐ I prefer to receive my official tax receipt by email to help reduce administrative costs. My email address is: _____

Thank you! Please return to: **Alzheimer Society of Nova Scotia**
112-2719 Gladstone St.
Halifax, Nova Scotia, B3K 4W6

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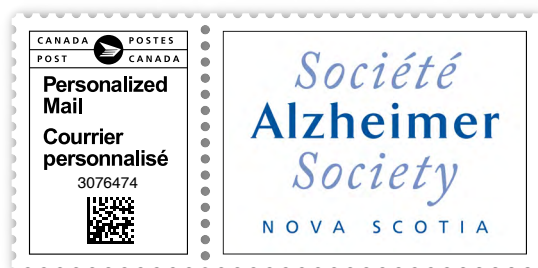


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