In the Loop

SUMMER 2021

Société Alzheimer Society
NOVA SCOTIA

ride for dementia
CYCLE of LIFE

Read about Dr. John Archibald's experience caring for his Dad, who is living with dementia, and his nine-day cycling journey around Nova Scotia in his honour on pages 12-15.

SUMMER 2021

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DR. JOHN ARCHIBALD, Dalhousie University

5,030 reasons to support ASNS!

Anne Barnes, Spring 50/50 Jackpot Winner

My name is Anne Barnes, and my mother has been on her dementia journey for over 12 years. She was first diagnosed with Frontal Lobe Deterioration. At the time, this diagnosis was not a surprise to our family. She had been exhibiting unusual behaviors such as errors in judgement on very simple things and being extremely paranoid about most everything.

Having this diagnosis should have given us some peace of mind and maybe even a few answers to the millions of questions going through our minds. But, we did not find that peace. Mom continued to deteriorate and was becoming increasingly angry and confused, which of course created great stress on her and myself as her primary caregiver. I was at a loss.

About four years ago, I agreed to support a dear friend by joining her at an ASNS support group and that is where everything changed for me. I learned through the amazing team at ASNS how to manage situations differently, how to look at things differently and how to act and not react when Mom is struggling. And for that, I cannot thank ASNS enough.

So, when I saw the 50/50 raffle opportunity, I did not hesitate to support it! I purchased my tickets and promptly forgot all about it until I received the most wonderful phone call on June 4 letting me know I was the winner and would be taking home $5,030! Once the shock wore off, I immediately put some aside for my grandchildren's education fund, and just because I wanted to, I bought myself a brand new living room chair! Wonderful feeling.

This is my story. I know first-hand the amazing work of the team at ASNS. I hope you will consider supporting this great organization and purchase your tickets today. And who knows, your phone could be ringing next time!

Building caregiver resilience

Catherine Shepherd, Regional Coordinator, Education & Outreach, Cape Breton

Originally published in the Cape Breton Post

Alzheimer's disease is often thought of as a family disease. I say this a lot when I'm helping people to understand Alzheimer's disease and other forms of dementia. What I mean by this is that caring for someone with dementia affects everyone in the family.

Caregivers play a huge role in the life of someone with dementia. As the disease progresses, the person with dementia increasingly relies on their caregiver and family members for physical, emotional, and social support. In my role with the Alzheimer Society, I have spoken to many caregivers. As they learn more about the disease from me, I'm continuously learning from them about their courage, challenges and how resilient they are.

Being resilient is the ability to adjust to change. There are a lot of changes that occur throughout the progression of the disease that affect the person with dementia and their caregiver. By learning more about dementia and strategies to help, caregivers are building their resilience and feel more prepared on their journey.

Recently I watched a webinar on the Alzheimer Society of British Columbia's website called Strategies for Building Caregiver Resilience. It offers some great tips and reminders on how to build resilience as a caregiver. The webinar highlights the acronym D-A-N-C-E explaining the core principles of caregiver resilience.

The D in D-A-N-C-E stands for don't argue. When caregivers understand and acknowledge that their reality maybe different from the person with dementia this can help to ease their distress and frustration. Meeting the person with dementia where they are in their reality is important. You can do this by adjusting your communication style and approach, and this will help to set you up for success.

Accepting the disease comes next. There are many emotions that you will experience as a caregiver and there's no right timeline or order in which these emotions occur. Accepting the diagnosis can be hard. But once you accept the situation, you can then move on to making adjustments to help with living well.

Core Principles of Caregiver Resilience: D.A.N.C.E.

D Don't argue

A Accept the disease

N Nurture your physical and emotional health

C Use Creative problem solving

E Enjoy the moment

From: *When a Family Member has Dementia by Susan McCurry*

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Self-care for caregivers is vitally important. The N in D-A-N-C-E stands for nurture your health. Caregivers give so much to ensure their person with dementia is well taken care of, but they also need to take care of their own physical and emotional health. Taking a break even for a short period of time can help you to recharge and refocus.

The C is for creative problem-solving which caregivers do every single day. Set realistic goals, be forgiving of yourself and recognize there is no perfect caregiver. We all learn from our mistakes and caregiving is a hard job. Give yourself some credit for doing your best.

Finally, E is for enjoy the moment. There will be good days and bad days but working on finding the positive in each day can help to build self-awareness and resiliency. Be mindful of what is happening and try creating a relationship with your person in the moment.

Another great resource to check out is a virtual presentation the Society hosted last month on YouTube called My Journey with my Mom. A daughter shares her story of caring for her mom who has dementia and offers first-hand experience and insights about her journey which many caregivers will find relatable. The video is available here: www.youtube.com/watch?v=19hsaSwWFml

It takes time and practice to build caregiver resilience and I have so much respect for all the caregivers I know. Please know that you're not alone and if you're looking for more tips or programs and supports to help you, call our InfoLine at 1-800-611-6345.

Looking forward to fall programming

Beth Bennett, Regional Coordinator, Education & Outreach
Antigonish, Guysborough & Pictou Counties

Learning virtually is not for everyone and we know it does not replace that face-to-face connection. However, over the past year we saw tremendous success with online programs. Families found a way to stay connected during isolating times, and at ASNS we reached people in Nova Scotia we never would have been able to reach. Some clients said they enjoyed connecting from the comfort of their own home. With these benefits in mind, the Society will continue to offer online programs in addition to in-person programming when we are able to.

As we head into the fall, there will be many families living with dementia who continue to use our services and some who will connect with us for the first time at one of our programs that we offer. Wherever you are on your dementia journey, it is important to know that there are a variety of programs, resources and services that can help.

Many caregivers across the province have made new connections in our Caregiver Support Groups. The groups are open to family and friends supporting someone living with dementia and provide an opportunity to learn, share and help each other through mutual support. All the groups are facilitated by trained volunteers or Society staff, and offered once a month at different times to fit different schedules.

Another great program for family and friends is the Family Caregiver Education Series. This six-week educational series was developed to help caregivers learn more about dementia, get connected to resources and plan for the future. This program is for educational purposes and each week there is a different presentation and a Q&A session with the presenter.

U-First!™ for Care Partners is an education program designed to increase care partner confidence and capability to reduce responsive behaviours. For those who take our Family Caregiver Education series, this is a next step for education. This six-hour workshop has a lot to offer with a goal to enhance the well-being of both care partners and those experiencing behaviour changes.

In addition to programming for caregivers, we offer a number of programs for people living with dementia. Artful Afternoon, a partnership with the Art Gallery of Nova Scotia, is a fun, relaxed, visual arts program for persons with dementia and their care partners. After running the program virtually this past year, we're aiming to welcome participants back to the Art Gallery in person this fall.

When we know better, we do better. The Society also offers public education on dementia-related topics through our monthly AlzEd virtual education sessions.

We have recorded these presentations with various guest speakers. You can find a playlist of recordings on our YouTube channel: www.youtube.com/alzheimerns. Being able to go back and watch these sessions has been beneficial for many.

This has been a time of change for all of us but together we are finding our way back to our “new normal,” with an exciting schedule for online programming for the fall. As Public Health restrictions evolve, so will our program offerings. Keep an eye on our website or call our InfoLine at 1-800-611-6345 for more information, or to discuss topics related to dementia. We are committed to keeping everyone safe and really look forward to seeing you online or in-person soon!

Check out the next page for a full list of our program offerings!

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.

OUR PROGRAM OFFERINGS

As we begin to welcome participants back to in-person programming, we'll continue to have virtual offerings. We hope this will provide the flexibility needed to ensure everyone can access our progams. Please contact our InfoLine at 1-800-611-6345 to learn more about how to register for these programs.

CONNECTION & SUPPORT

InfoLine 1-800-611-6345

InfoLine is a confidential telephone service provided by a team of knowledgeable and caring staff. We provide information on topics related to Alzheimer's disease and other dementias, discuss questions and concerns, and provide referral to programs and resources.

Caregiver Support Groups

These confidential groups for caregivers provide an opportunity to learn, share, and help each other through mutual understanding and support. Facilitated meetings are held once a month.

Connections Hub

The group provides a dementia-friendly space for persons living with dementia to connect socially. The program is facilitated by an ASNS staff member.

Artful Afternoon

This program is a partnership between ASNS and the Art Gallery of Nova Scotia for persons with dementia and their care partners. It is a social, interactive program combining art making and education in a dementia-friendly environment. Participants are not required to have any prior experience in art to attend.

Coffee & Conversation

This is a 6-week program for persons with dementia to receive peer support to discuss their own experiences related to dementia.

LEARNING & EDUCATION

Online Public Education Sessions

Connect with the Society once a month for information about dementia and related issues in our AlzEducate series. You can find the archived sessions and register on our website at www.alzheimer.ca/ns/virtual-meetings.

Family Caregiver Education Series

This six-part education series supports families and care partners of persons newly diagnosed with dementia. Each session consists of a presentation and a question and answer period.

Shaping the Journey™

Shaping the Journey is a seven-session educational program designed for people experiencing the early symptoms of Alzheimer's disease or another dementia, and a care partner.

U-First!™ for Healthcare

This six-hour workshop develops common knowledge, language, values, and approach to caring for people with Alzheimer's disease or other dementias. It is open to frontline staff of long-term care and home support agencies across Nova Scotia.

U-First!™ for Care Partners

This six-hour workshop is an innovative education program is designed to increase care partner confidence and capability to reduce responsive behaviours, while enhancing the well-being of both care partners and those experiencing behaviour changes.

Annual Provincial Conference

Each year, we host a conference where healthcare professionals, care providers, educators, researchers and students can exchange the latest on research and dementia care in Nova Scotia.

ASNS ANNUAL PROVINCIAL CONFERENCE
Supporting Dementia in all its Diversity
OCTOBER 28, 2021

Dementia has many faces. Beyond a unique diagnosis, people hold diverse identities. Let's talk about making dementia care more inclusive for all.

2021 Annual Provincial Conference: Supporting Dementia in all its Diversity

October 28, 2021

www.asnsconference.ca

EARLY BIRD REGISTRATION NOW OPEN UNTIL SEPTEMBER 10

Be sure to register for our annual provincial dementia care conference taking place **Thursday, October 28, 2021.**

For $25, enjoy a day jam-packed with curated educational content and opportunities for exchange with fellow attendees, speakers, ASNS staff and sponsors.

This year, the conference will be delivered through a friendly, interactive virtual platform with LIVE speakers!

Join us for a day exploring:

- Intersectionality in dementia care and research
- Supporting rare or complex dementias
- Dementia inclusive communities

Stay tuned for the full program snapshot in September.

Register today at www.asnsconference.ca

Early bird rate closes September 10, 2021. Regular conference rate of $35 will apply.

> *"I was hesitant about the digital format, but this was one of the most engaging zoom presentations I've attended" – 2020 Virtual Attendee*

Keeping it safe online

Beth Bennett, Regional Coordinator, Education & Outreach Antigonish, Guysborough & Pictou Counties

Many of us are spending more time online than ever before. Logging on for online shopping, paying bills, and connecting with friends and family is part of our lifestyle now. If we are spending so much time online, how can we ensure we're doing it safely?

I spoke with Dawn Thomas, Seniors' Safety Coordinator for Digby and area Seniors' Safety Program to ask her a few questions about how to stay safe online. Dawn and the other Seniors' Safety Coordinators across the province work in partnership with the RCMP and local policing agencies to ensure seniors are safe at home for longer. One of the areas they focus on is online safety and fraud and scam prevention.

Scams come to us through phone, email, door to door, mail and social media. It is important that we become educated on what scams are out there, how to surf the net safely and take steps to protect our identity, especially for seniors and those who are living with dementia.

"Right now, one of the most popular scams in Nova Scotia is the bank manager scam," says Dawn. "You receive a call, and they say it's the bank and they want you to go out and buy some iTunes cards to help someone in need. In reality, it's the senior who is affected. I had one gentleman who lost over $8,000 in two days. It wasn't even the money that was an issue for him, it was the emotional stuff that came with it. It was heart wrenching because he really thought he was doing the right thing."

Targeting people online is becoming more frequent and it's important to know what to watch out for. Phishing scams are emails that look like they are coming from a specific company, but they're not. Smishing is text messages you receive that are not real. Often, you can look for spelling mistakes to see if the email or text you are receiving is legit or not, keeping in mind that most government agencies are not going to email you, they're going to contact you by lettermail.

"The other popular scam right now is merchandise scams," says Dawn. "People claim to be selling cars, animals and rental properties and ask you to put down a deposit but there really isn't anything for sale. We also see extortion scams, so you think it's the CRA calling, and they threaten that you haven't paid your taxes, and they want your social insurance number and make threats to call the police."

All these scams can be frightening, and the scammers can be very persuasive. Ideally, if you get a call, text, or email, don't share numbers or personal information. Have someone help you do your research and call the company directly to see if they are who they say they are.

"A lot of older adults are on Facebook, so we talk about social media behaviour and how to be careful with what you share and like," says Dawn. "For example, Jesus is not on Facebook. You might share a prayer or a child that is sick thinking you are doing the right thing but you're not drawing attention to the picture you shared, you're drawing attention to potentially becoming a victim of a scam. Saying 'amen' to a meme can put you at risk of being scammed. This is a classic example of how scams prey on your emotions – you're better off saying a silent prayer than commenting."

"We talk a lot about what is safe to like and share," says Dawn. "It's important to know that your activity leaves a digital footprint. The internet is watching and addressing what they think you're going to click on and share."

Cyber safety and Internet security is tricky even for those of us who understand how to work the Internet. When you have someone doing online banking whose memory or judgment is impaired, it is important for caregivers to work with them to do it safely.

"We teach people what safe sites are," says Dawn. "A good tip is to look at the lock in the corner of your search bar. If the lock is open, it's not a safe site. If the lock is closed, you're good to give it a whirl. We also talk about safe passwords and how often you should change them. Passwords should be secure and include things like symbols, numbers and capitals. Do not respond to anything online that makes you sad or has a timeline stating you must act in, 48 hours or less for example. Those are red flags."

With education and support from family, we can do our best to ensure everyone has a safe online experience. There are lots of resources to help you learn about internet security. Families should stay involved with what seniors are doing online and caregivers can work with those you care for to help keep their identity safe.

For more tips on how to stay safe online, please visit our website, www.alzheimer.ca/ns. To learn more about the Seniors' Safety Program and what it offers, find a recording of one of the our AlzEd sessions with guest speaker, Dawn Thomas on our YouTube channel, www.youtube.com/alzheimerns.

Tips to help you stay safe online:

- Install and run anti-virus software regularly
- Always check to ensure the emails you receive are from a trusted source
- Never give out private information such as credit card numbers or bank statements
- Do not open attachments from unknown senders
- Do not visit any unfamiliar or suspiciously named websites
- Avoid calls that claim you have won a good or service
- Do not respond to numbers asking for private information or promoting deals
- Do not use any open and/or unsecure Wi-Fi networks
- Reduce the amount of personal data you make available on your social media profiles
- Do not add unknown people to your social media network
- Do not use yours or your relative's name, birthdays, or private information as your password

Source: Alzheimer Society of Canada Online Safety

Confessions of an amateur caregiver

Dr. John Archibald, Dalhousie University

Friday, February 26, 2021. I will never forget it. It was the day my father moved into long-term care.

At 10:00 AM my mother and I got Dad into the car and drove the short distance to the facility. 20 minutes later, we 'handed him off' to the staff at the front door. They were kind and understanding and prepared to receive him. We weren't allowed in the building. All we could do was say our goodbyes and assure Dad that he was in good hands, that we'd see him again soon.

John as a child with his Dad.

Dad didn't know what was happening. As we backed away, he looked at us with confusion; he was wondering where we were going.

Back in the car Mum and I had a good cathartic cry, the kind that only happens when one feels that a huge weight has been lifted off one's shoulders. We recovered, took a brave-face selfie, and drove slowly to the next town over. We got some take-away coffees and sat in the sun looking out at the ocean. It was a sunny, brisk winter day — perfect for reflection. We had some laughs, cried some more and talked about the mysteries of dementia.

The previous two weeks had been a whirlwind of anxiety and emotion. My father was diagnosed with Alzheimer's disease in 2014, and while his cognitive and physical decline was for some years quite gradual, by mid-2020 it had begun to accelerate. Things came to a head in mid-February 2021 and I made the hour-long drive to stay with my parents and help out 24-7.

'Unprepared' doesn't even begin to describe how I felt.

My sisters and I had each spent time caring for Dad over the years – afternoon visits, weekends, and occasional week- or month-long stints that gave Mum some respite. And my parents were themselves well-prepared. After Dad's diagnosis they'd taken advantage of services provided by the Alzheimer Society of Canada, in particular, their Shaping the Journey: Living with dementia program. It taught them about the psychosocial and physical challenges they would soon be facing and helped them make sound choices. They had done their homework. We three sibs watched, learned and helped to the extent that our busy lives allowed.

But until I moved in, I hadn't appreciated just how far Dad's health had slipped and how much pressure my mother had been under. The demands of the job had ratcheted up over the years, slowly, almost imperceptibly at first but with a quickening pace that had begun to take a toll on Mum's mental health. Dad now needed help in almost every way, not just during the day but several times a night as well. With the benefit of hindsight, she was clearly suffering from caregiver burnout. I felt guilty for not recognizing it sooner.

Mum was exhausted and I felt like an incompetent substitute. What does Dad need in this situation, in that? It was difficult for him to tell me. Speech and vocabulary had been an issue for years and it had only gotten worse. What can I do to ease Dad's frustration and anxiety? How can I ease Mum's?

I learned on the job, as one does when there is no choice.

Mum taught me Dad's daily routine, such as it now was. He was no longer able to do most of the things he had previously enjoyed. He'd long since given up reading – which had been a passion for as long as I could remember – and the puzzles that had more recently occupied his mind were now also shelved. He liked watching TV, pedaling gently on his recumbent exercise bike and, for short periods of time, looking at photo albums. That was pretty much it.

And naps. Dad took lots of naps (I come by it honestly). But just because his eyes were closed didn't mean he was asleep. On one occasion Mum and I were having a hushed conversation in the kitchen when Dad suddenly spoke up from the next room: "What about me?"

Our jaws dropped; my heart sank. Dad was tired of being talked about like he wasn't there. I knew this was a no-no and kicked myself for not doing better. As the dementia journey progresses, it becomes increasingly difficult to avoid having to speak for – and about – your loved one in their presence. But anything that can be done to include them in conversations and social interactions, even passively with regular eye contact, is worth the effort. For them and for you.

As Dad's situation continued to evolve, routines and practices that had worked well even a few weeks back became problematic. Sometimes they failed spectacularly (why on Earth did I leave Dad's walker in the trunk of the car?! He needs it now!). Mum and I learned about 'sundowning' (or 'late-day confusion') and took steps to minimize its effects.

Probably the most important caregiving lesson learned was this: be prepared to tear up the script at a moment's notice. As time goes on, the need for a flexible, adaptable care plan becomes more and more important. This can be difficult for people who, like my parents, were encouraged by dementia specialists to build their journey around healthy routines. It's great advice but it is possible to follow it too strictly.

In our spare time, and with regular input from our extended family, Mum and I navigated the

John and his Dad, July 9, 2021. Photo by Anne Launcelott.

complexities of the long-term care placement system. This was of course something that Dad had consented to ages ago, and by this time he'd been on a wait list for over a year. Despite the pandemic, we were lucky to be offered a place for him nearby. It all happened so fast – too fast, actually, but I doubt there is an easier way.

There was a mountain of paperwork to be completed (the Continuing Care and facility staff were amazing) and we needed to arrange for a COVID-19 test before Dad could move in. We did our best to explain to him what was going to happen in the coming days. We printed out a simple map to show him how close to home his new home would be. We showed him pictures of inside the building posted on the facility website. We even did a drive-by the day before so that the outside would look familiar to him.

In the end none of this mattered. There were times when Dad seemed to appreciate where all this was heading, but most of what we told him didn't stick – the inability to lay down short-term memories is one of the most challenging aspects of Alzheimer's disease and other dementias. Occasionally we saw this as a blessing rather than a curse. Moments of intense frustration were quickly forgotten. His early morning COVID-19 swab had been bothersome, but by lunchtime he had no recollection of it.

Dad's last 24 hours at home were full of 'lasts', some more difficult than others.

The last supper (Mum made salmon, Dad's favourite).

The last night in front of the TV (Dad laughed at slapstick Kramer in a Seinfeld re-run, as he always did).

The last time through the bedtime routine. The last breakfast. As we finished up Dad innocently asked: 'what are we doing today?' Mum and I struggled to keep it together.

The last car ride and the doorway hand-off.

My feelings immediately afterward were an intense mixture of sadness, guilt and relief. Sadness, obviously; guilt over my role in shifting the arc of Dad's life in such an impossibly strange way; relief that he was now in the hands of professionals and I was no longer directly responsible for his safety and wellbeing.

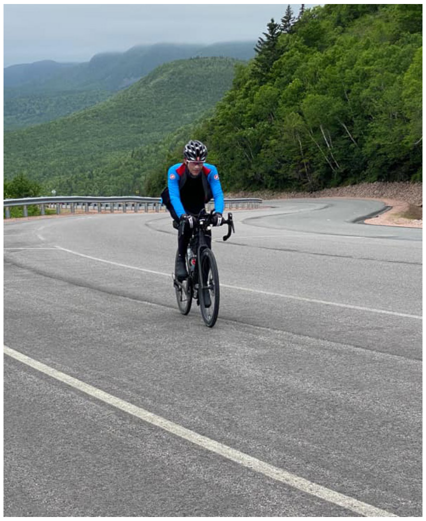
For me, the transition from spending two weeks straight with my father to suddenly not having him there at all could not have been more jarring. For my mother, it felt like her 50-plus-year marriage had ended. It hadn't, of course, but there was no denying that at 10:20 AM on that late-February day, their relationship changed forever.

We'd been warned that the transition to long-term care would probably be more difficult for Mum than for Dad. They were right. Four months on, however, Mum has found her feet again, relieved that Dad has adapted to his new environment and new routines. My parents have moved on to the next stage of the dementia journey.

We are proud of them both.

Cycle of Life - Ride for Dementia

On July 1, 2021, Dr. John Archibald set out to ride his bicycle around Nova Scotia in support of dementia care and brain donation. He cycled the ~2,400 KM perimeter of the province in 9 days, persevering through rain, cold and a post-tropical storm (and a little bit of sun). He raised funds for us at the Alzheimer Society and the Maritime Brain Tissue Bank via the Dalhousie Medical Research Foundation. If you'd like to support this initiative, his donation portal is still open at www.ridefordementia.ca. Or, you can fill out and return the reply form below. All funds donated though this reply form will be split with the Maritime Brain Tissue Bank.



John cycling the Cabot Trail.

Name: ______________________________

Full mailing address: ____

____

Yes! I would love to support dementia care and brain donation in Nova Scotia through the Cycle of Life - Ride for Dementia.

I'd like to make a one-time tax-deductible contribution of:

☐ $20 ☐ $50 ☐ $100 ☐ $ __________

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.ridefordementia.ca**

Interested in learning about becoming a monthly donor or planning a legacy gift? Contact Denise at 902-229-6093 or denise.collier@asns.ca.

In the Loop

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No one should face dementia alone.

Read how you make that possible in our latest newsletter.