Fall 2018 / The quarterly newsletter at the Alzheimer Society of Nova Scotia

# HAVE YOUR DONATION MATCHED ON GIVING TUESDAY



Your donation will be matched\* by

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Online: www.alzheimer.ca/ns | Phone: 1-800-611-6345

By Sarah Lyon, ASNS Staff

Early in November, right after Halloween, the marketing campaigns begin for two days dedicated to shopping: Black Friday and Cyber Monday. But increasingly awareness has been raised for another special day, Giving Tuesday.

This year on November 27 the Alzheimer Society is pleased to have Deloitte back as a matching sponsor. This means your donations to support Nova Scotians facing the realities of dementia, will double!

"We appreciate the support we get from all donors and our corporate partner Deloitte," says Sarah Lyon, ASNS Director of Philanthropy. "Imagine being able to double the impact of your gift through a quick phone call or visit online. We know donors truly appreciate the matching donation."

We hope you save the date and kick of the holiday season on Giving Tuesday. Your donation can be made online or over the phone at 1-800-611-6345.

# 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:

www.alzheimer.ca/ns or Mark at mark.sharkey@asns.ca, 902-422-7962, ext. 241

# **Contact Us**

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902-422-7961 1-800-611-6345

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Dawn Archambault 902-790-4189 dawn.archambault@asns.ca

# **South Shore**

Cheryl MacKay 902-523-1614 cheryl.mackay@asns.ca

# ARE YOU LOOP?

# Coming up...

# **November 27**

Giving Tuesday

# January 16

Alzheimer Awareness Breakfast, Sydney

## January 25

Alzheimer Awareness Breakfast, Bridgewater

# January 29

Alzheimer Awareness Breakfast, Halifax

### May 5

Walk for Alzheimer's, Halifax & Sydney

### May 9

Walk for Alzheimer's, Truro & Annapolis Valley

If you have any questions about the upcoming events, please contact our office at 1-800-611-6345.

Support groups are offered on various dates around the province.

# **Making 35 Connections**

# By Kirstie Creighton, Director, Program Development

Nova Scotia, you did it! You invited us in to your communities – 35 communities we had never been in before – to give public education sessions. All within the first eleven months of 2018. Why is this milestone important? It was a goal the programs and services team set at the end of last year in recognition of the Society's 35 years of service. Among the 35 communities were: Bay St Lawrence in the East, the Acadian community of Amirault Hills in the West, Big Tancook Island in the South and the Springhill Fire Department in the North. We connected with over 1000 new people across the province.

We met in fire halls, community centres, churches, hospitals, education centres, libraries, and legions. We met with women's groups, faith groups, seniors' clubs, immigrant organizations and neighborhood associations. We shared information about the 10 signs and symptoms of dementia, good brain health, and programs and services offered by the Alzheimer Society of Nova Scotia.

By *intentionally* reaching out we were able to connect with communities that we have not had the opportunity to work with in the past. With the Immigrant Services Association of Nova Scotia, one conversation turned into a two hour workshop, simultaneously translated into five languages, for 35 new Canadians from around the world.

Some of this outreach led to well beyond the initial 45 minute public education presentations. In East Preston we began with a general information session as part of a Mental Health Workshop series. After that initial presentation, community members voiced an interest in learning more. Over phone calls and face-to-face meetings we developed relationships and were invited back to facilitate the six part Family Caregiver Education Series. Most recently we presented as part of the regular Sunday service at the East Preston United Baptist Church where we were part of a panel discussing different aspects of mental health. One community member spoke about how the information, education and support he received

# **Continued on Page 4**



# **Continued from Page 3**

from the Alzheimer Society helped him on his journey as the primary caregiver for his mother living with dementia.

This process of intentionally reaching out and Making 35 new connections was of benefit to both ASNS staff and the greater Nova Scotian community. Elizabeth McMicheal, a participant at the Clementsport Legion presentation said, "Thank you so much for your presentation on Alzheimer's this afternoon. There are so many things we don't know but it is good to have people like yourself helping to spread some understanding. Thank you for your time"

"I love presenting in new communities and to new groups," says Beth Jackson, Coordinator, Education and Outreach for Guysborough, Antigonish & Pictou County. "I often say getting out and meeting new people is the best part of the job, especially when you can help to educate about dementia and connect families who are looking for more support to programs and services. Making new connections is an important part of outreach and so is building those relationships. The Making 35 Connections project really brought that to the forefront and gave us a new goal to work towards."

We thank you for inviting us into your communities and we look forward to building on the new relationships we have made in 2018.

If you would be interested in hosting a public education session, or hearing more about our programs and services, please do not hesitate to contact Kara Gouthro-Murgatroyd, Coordinator, Education and Support Services at 902 422 7961 or email at kara.gouthro-murgatroyd@asns.ca



# Canadian Charter of Rights for People with Dementia

# By ASNS staff

Six times a year, a group of Canadians come together as the Alzheimer Society of Canada Advisory Group of People Living with Dementia. This past September the group – which includes Nova Scotia's Marilyn Taylor – launched the Canadian Charter of Rights for People with Dementia.

"Because of our experiences living with dementia, there are a number of topics that the advisory group would like to have discussed with all Canadians," says Marilyn. "The Canadian Charter of Rights for People with Dementia is our first big project."

Canadians living with dementia are entitled to the same human rights as every other Canadian, as outlined in the Canadian Charter of Rights and Freedoms. However, stigma and discrimination are huge barriers for people with dementia and often contravene these rights.



Sandra & Marilyn

"There is still a lot of stigma surrounding a diagnosis and that has a negative impact on people living with dementia," explain Linda Bird, Director of Programs and Services at ASNS. "The charter explicitly states the rights of people with dementia, at all stages of their dementia journey. It is an acknowledgement and reminder for all of us to bear in mind when we are interacting with, caring for, developing programs and policies that affect persons living with dementia. We all need to be educated about the charter and live it day to day. We need to ask ourselves, are we or are actions upholding these charter of rights? If not, what needs to change and how can we do better?"

The Charter defines seven explicit rights to empower Canadians living with dementia to self-advocate, while also ensuring that the people and organizations that support them know and protect their rights.

"My hopes for the Charter is three-fold," Marilyn begins listing. "One, that people with dementia realize they have rights and are empowered by them. Two, that people who do not have dementia realize that those of us who do, have rights and deserve to be treated as such. And three," continues Marilyn. "That when our rights are not respected, there is recourse."

In this edition of In the Loop we have included the charter, but if you would like a one page copy, you can request that through the Alzheimer Society of Nova Scotia. Marilyn hopes you post it where people with dementia work, live and interact with those who don't have the disease, so that they can be mindful that, "we are still people, and we are still here," says Marilyn.

At the Alzheimer Society of Nova Scotia we have enlarged the Charter and posted it as soon as you walk into our office. And no one told Marilyn before she came through the doors recently.

"I walked in to the office and saw the charter right there in the entrance. I was weak kneed and awe stricken. ASNS read it and understood its content and placed the charter there for all to see! Talk about our voice being supported! Thank you ASNS."

# Alzheimer Society



# CANADIAN CHARTER OF RIGHTS FOR PEOPLE WITH DEMENTIA

As a person with dementia, I have the same human rights as every Canadian as outlined in the Canadian Charter of Rights and Freedoms. The following charter:

- Makes sure people with dementia know their rights,
- Empowers people with dementia to ensure their rights are protected and respected, and
- Makes sure that people and organizations that support people with dementia know these rights.

As a person with dementia, the following rights are especially important to me. I have the right:

- 1 To be free from discrimination of any kind.
- 2 To benefit from all of Canada's civic and legal rights.
- 3 To participate in developing and implementing policies that affect my life.
- To access support so that I can live as independently as possible and be as engaged as possible in my community. This helps me:
  - Meet my physical, cognitive, social, and spiritual needs,
  - Get involved in community and civic opportunities, and
  - Access opportunities for lifelong learning.
- To get the information and support I need to participate as fully as possible in decisions that affect me, including care decisions from the point of diagnosis to palliative and end-of-life care.
- To expect that professionals involved in my care are:
  - Trained in both dementia and human rights.
  - Held accountable for protecting my human rights including my right to get the support and information I need to make decisions that are right for me.
  - Treating me with respect and dignity.
  - Offering me equal access to appropriate treatment options as I develop health conditions other than my dementia.
- 7 To access effective complaint and appeal procedures when my rights are not protected or respected.

It will take the effort of every Canadian to protect and respect the rights of people with dementia so that we are seen as valuable and vital community members.

# I went to the doctor, you should too

By Catherine Shepherd, originally in Cape Breton Post on Nov.3rd



The past few months I have written here about what to do when you are experiencing the signs of dementia, how to talk to your doctor about those symptoms, and what plans to start making if you do have a diagnosis of Alzheimer's disease or another dementia.

But today, something different. I want you to hear from a Nova Scotian who has travelled that journey and lives with dementia. Not everyone is comfortable sharing their story of living with the disease, but Sandra wants to because she wants others to know that yes, you don't want to hear from a doctor that you have dementia, but that if you do, getting a diagnosis and getting supports to help you, is the best thing you can do in the long run.

So please stop for a few minutes, grab a cup of tea, and read the words Sandra has to share. I can guarantee you if you take the time, you will gain knowledge, admiration and respect for all those on the dementia journey.

"I heard 'you're too young, you can't have dementia' so many times. I was only 54," starts Sandra. "But I knew something was wrong with me. I was having a hard time remembering things that I had done. I used to have a very good memory, very good recall and I was starting to forget my work as an accountant. It was taking me longer to do my job; I would have to look up laws, I forgot passwords, I would get lost driving to work. And the thing is, I would keep passing the memory tests! I was lucky because my doctor kept sending me, over and over again."

But Sandra wasn't telling the doctors everything. On top of experiencing memory loss she was also having hallucinations. When she finally did mention that she was having these hallucinations, doctors were able to piece together that she had Lewy Body dementia.

"I tell people to always tell the doctors everything. I should of. And I tell people to bring someone with you to the doctors. I brought my daughter Lora. I knew the diagnosis was going to be dementia, but I was hoping that it would be something else. I was devastated when I got my diagnosis."

Having her daughter present with her at doctor's appointments was very helpful for Sandra. Lora was able to tell health care professionals what symptoms she saw, but also to hear the recommendations doctors made after the diagnosis, because Sandra pretended to be ok in the office, but was in shock. She admitted as much on the drive home to her daughter.

"We talked a little in the car about next steps, but to be honest, I went into hibernation for about a year. I would take the dog for a walk and go straight back inside. It was Lora, who had heard from the doctors what kind of positive steps I could be taking, and not seeing me act on them, got me back to my GP, who got me in touch with

Alzheimer Society of Nova Scotia, which is when everything changed. Had it not been for having my daughter and son Derek as my partners in care throughout this journey, my doctor who was always supportive, and the Alzheimer Society who got me in to programs, I believe I wouldn't be where I am today. I would be homeless in fact. I was scared to go to the doctor and I wouldn't have if I didn't have my daughter – who was pregnant with my first grandchild at the time – with me."

Sandra knows from coming forward as an advocate and sharing her story, that people who hide from a potential diagnosis until it's too late, often end up in a crisis situation which is why it's important to reduce the stigma around dementia.

"Today I am a whole different person then when I was diagnosed and hid from the world. The support I have has made me realize that I am still a person, still valuable, and that I and those who have or support someone with mental health, still have rights and a voice. We need to reach out and help more people talk to their health care professionals, whether they may have the disease or are a partner in care, by doing so, we help others have a better quality of life with dementia."

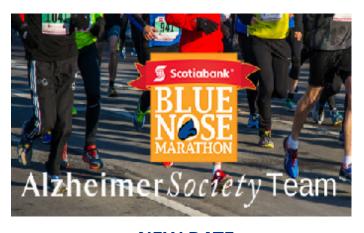
Just a few years ago, after her diagnosis, Sandra wasn't an advocate, she was barely leaving her house to do her favorite hobby: exploring the outdoors.

This past month she climbed four mountains in Peru. Nothing is keeping her back.

# Want to hear more from Sandra?

Visit www.youtube.ca/AlzheimerNS\_and watch videos of Sandra sharing her tips for living with the disease.

If you have questions about visiting your doctor, or talking to your family and friends, please call the Alzheimer Society of Nova Scotia at 1-800-611-6345



NEW DATE June 6-9, 2019

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You get Free Registration in any Blue Nose race:

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

Get moving with the Alzheimer Society Blue Nose Team!

# The Importance of Planning

Submitted by George Clarke, Lawyer, Boyne Clarke



When I learned that Aretha Franklin had died without a will, I felt compelled to write the article below. As an estate lawyer, it seemed like an opportunity to remind people about the importance of planning. As a musician, and fan of Aretha, her death struck me personally and inspired me to write. At the same time, it also reminded me of how often, in my practice, I encounter families experiencing dementia and how important it is to ensure that an estate plan is in place before it's too late.

In 1997, at the age of 69, my mother began to experience memory loss and the onset of dementia which turned out to be Alzheimer's disease. Over the course of the next several years, these symptoms became worse, and my mother experienced increased anxiety and distress as the disease progressed. It had a huge impact on our family, but

particularly on my father and sister who lived with the daily progression of mom's illness. She died in 2007 after ten very long and extremely difficult years. It took a long time for us to recover.

During my mother's illness, my father discovered the Alzheimer Society and the educational programs they provide. He learned that it is a place where people can connect with others who are experiencing the disease. One of the first questions they ask is whether there is an estate plan in place because they understand that a will is an effective means to ensure for the provision of family and other loved ones. In addition to making adequate provision and transition of assets, a will is an opportunity to make a gift to charities such as the Alzheimer Society to allow for their continued support of those affected by dementia.

Fortunately, my parents had visited their lawyer to put a complete estate plan in place before mom was no longer capable. However, many people I meet in my work either never plan or come to me when it is too late due to the progression of their dementia. It creates untold stress on a family with predictably unfortunate outcomes when there is no plan in place.

If you or a family member is experiencing memory difficulty do what my dad did: reach out to the Alzheimer Society. And visit your lawyer about making an estate plan. It's easy and not at all expensive.



# Aretha Franklin Died Without a Will – Who Gets the Pink Cadillac?

Submitted by George Clarke, Lawyer, Boyne Clarke

Aretha Franklin died on August 16th, 2018. Over a career that spanned almost 50 years she recorded 112 charted hits on Billboard, she had 17 top-10 singles, 100 R & B entries (including 20 number-one R & B singles) making her the most charted female artist of all time. She sold more than 75 million records worldwide and won 18 Grammy Awards. One can only imagine she died a very wealthy woman.

She seemed to have it all. Yet for all her accomplishments and presumed wealth, the Queen of Soul had no will.

As a lifelong musician, I was devastated at the news of Aretha's death. I grew up listening to her music and playing her songs in bands (and still do to this day). I imagined myself as her drummer backing her up on "Think" with Ray Charles and the other guys in the Blues Brothers movie. As an estate planning lawyer, I was surprised (but not shocked) to hear Aretha had no will. Many people die without a will, including the rich and famous. In fact, over 50% of Canadians die without a will. The woman who earned the RESPECT of tens of millions of music fans died in Michigan, so her estate will be dealt with according to the laws of that state. But what would happen if Aretha lived in Nova Scotia? The answers are found in a provincial statute called the Intestate Succession Act, which governs the estates of people who die without a will.

### In Nova Scotia

Without a will, Aretha had no executor, which means that someone would have to apply to the Probate Court to be named personal representative of her estate. If she had been married, her spouse would have been entitled to apply. However, she was twice divorced and was not married at the time of her death. She had a longtime companion, Willie Wilkerson, but "companions" or common-law spouses don't qualify in this situation (more on that later).

She had four sons, so one or more of them could apply but they would have to live in Nova Scotia to be eligible. If they did not live here (and they don't), they could still apply, but only if the Public Trustee waived the right to

apply in priority to them as non-residents. In this case, the Public Trustee would be unlikely to waive the right given the value of the estate.

Once a personal representative is in place, who gets the Pink Cadillac and all the rest of it? Willie would not receive anything because companions and common law spouses are not recognized under our estate laws. Therefore, the estate would go to the four sons in equal shares outright and unconditionally. If Aretha had died at an earlier age while her children were young, they would inherit her wealth when they turned 19 with no strings attached. Remember, there is no will so there are no trusts.

Because probate (or administration) is required, probate fees would be paid on the value of Aretha's assets. In addition, all filings at the Probate Court are a matter of public record, so there would be no privacy regarding her estate assets and beneficiaries.

If Aretha had made a will she would have appointed one or more executors of her choosing. She could have dealt with her assets as she had seen fit, including creating trusts for some or all of her beneficiaries and giving assets to charities, had she been so inclined. She might have been able to direct certain assets to trust outside of her estate thereby saving money on probate taxes.

When Prince died in 2016 he had no will. In the aftermath of his death over 45 people came forward claiming to be heirs of his estate. The fallout in the Franklin estate remains to be seen. However, I can confidently state that a will, even a simple one, would have provided certainty and direction for Aretha's family.

Most of us do not have the kind of wealth Aretha and Prince left behind. However, regardless of your worth a will is important to have and will provide you with the peace of mind knowing that your estate will be distributed as you direct.

If you are interested in learning more about preparing your will & estates planning, we have a skilled team of <a href="Estates lawyers"><u>Estates lawyers</u></a> who would be happy to help.



for those with dementia and their partner in care

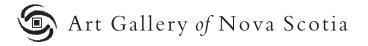
Be our guest at the Art Gallery of Nova Scotia for an artful outing. Join us in this dementia-friendly and comfortable setting for a descriptive tour and discussion of a variety of artworks in the gallery, followed by a cup of tea or coffee. An inspiring and fun way to spend your Tuesday morning!

LOCATION: Art Gallery of Nova Scotia, 1723 Hollis Street, Halifax TIME: 10:30–11:30 a.m.

DATES: November 6, 2018

December 4, 2018 January 8, 2019 February 5, 2019 March 5, 2019 April 2, 2019 May 7, 2019 June 4, 2019

**NO COST BUT REGISTRATION IS REQUIRED.** Registration on a per tour basis. Space is limited. To register, call the Alzheimer Society of Nova Scotia at (902) 422-7961, Ext. 224.







# **Caregiving During the Holidays**

By Beth Jackson, Coordinator Education & Outreach, Guysborough, Antigonish & Pictou County

The holidays are coming up quickly and it can be a very busy time for us all. With celebrations to plan, shopping to do and family and friends to visit, there's often a lot to check off the to-do list.

If someone in your family has Alzheimer's disease or another dementia, holiday traditions can change. For some care partners, the holidays can become a stressful time of year and many families experience a sense of loss.

It's important to recognize that there will be losses with dementia and families may not be able to do all of the holiday traditions the way they once did, but that doesn't mean you can't continue to enjoy the holidays.

Ella Wallace was a caregiver for her mother and shares her experience with caregiving during the holidays.

"Mom was the most beautiful decorator," says Ella. "She helped to decorate the tree with me for as long as she could and just did what she wanted when it came to decorating. After Mom moved to long-term care, we continued to make sure she had decor in her room that she enjoyed like a small tree, door hangings and light up ornaments on her dresser."

Knowing what the person with dementia enjoys and including that in your holiday planning is important.

"It's important to keep it simple and just do what you can," says Ella. "On any special occasion, I would try and do something a little different even if that meant a treat from Dairy Queen. On Christmas Day, I would take a plate of my homemade dinner to Mom and she always enjoyed that."

Ella also talks about the importance of letting the little things go and remembering that when it comes to caregiving finding humour is so important.

"Mom would often open up a gift on Christmas Eve and the other presents on Christmas Day. Sometimes the name tags and gifts got mixed up and I would have to ask the rest of my family what they gave Mom, but it didn't matter," Ella chuckles. "The most important thing was that she enjoyed it and it kept her busy."

There are many things to think about when it comes to holiday planning for someone with dementia. Check out the tips we have written below and if you have questions or would like to speak with one of the Alzheimer Society staff, please call us at 1-800-611-6345 or email

# **Holiday Planning Tips**

- Make plans as early as possible, especially travel plans
- Keep up with daily routines that are important for you and the person with dementia
- Ask the person with dementia if they would like to contribute during the planning stages of the holiday event or during it
- Choose a familiar place for a holiday event that has a quiet space
- Keep celebrations small if you can
- Be open to adapting old traditions to new traditions
- Food is an important part of tradition and you can include that no matter where you are
- Play traditional music such as carols or hymns
- Continue to take photographs
- Share communications tips with relatives and friends who may not know the best way to communicate
- Try to relax and enjoy the moment

# Championing Change in Dementia Care Recapping the Annual Conference

By Heather Murdock, ASNS staff

Over two days in October close to 250 health care professionals, support care providers, researchers, educators, and care partners gathered for the 29th annual ASNS provincial conference at the Doubletree Hilton in Dartmouth. Over those couple of days, registrants heard from people across the province who shared their innovative approaches to supporting and improving the quality of life for those living with dementia.

Among the highlights for many was a video clip of a dialogue between two women, Sandra and Marilyn, who are living with dementia. They discussed their experiences of change, stigma, fear, connections and hope as they continue to live well. They shared strategies that help them manage day to day. They are a remarkable duo.

Change in dementia care needs champions. Presentations from long-term care facilities on what they are doing to enhance quality of care for their residents, are prime examples of that. Northwood told us about two initiatives they've implemented; Kaye's Place is a home like space that families can use when visiting their family members away from the hustle and bustle. Hi-tech with Heart is another new initiative where their home care workers engage their clients with digital tools such as Skype and social media to connect the client with their friends and families. Rosecrest Communities shared some creative approaches and strategies they use to reduce responsive behaviours and improve quality of care. Brittney Amirault from Villa Acadienne shared their experience of working with a local photographer and a nursing student, on an engaging and fun project. With the help of the residents' families, they took pictures of their

residents and documented biographies about their lives and accomplishments. The project helped staff see the residents with new eyes, that the person is them, not their dementia. Arts Canopy demonstrated the benefits of participating in arts based programming for people living with dementia fostering social interaction and inclusion, a sense of worth.

Conference attendees were reminded that some individuals being admitted to long-term care arrive with life-long mental health and/or addictions. Substance use can further impact the abilities of people living with dementia and consideration to the management of the addiction is crucial. Dr. Mekary encouraged us to keep moving! There is much research suggesting that exercise may help keep the brain healthy in old age. He described the Acadia Active Aging program where Acadia honours students are paired with seniors in the community for one on one instruction to increase physical activity.

Thank you to the conference sponsors!





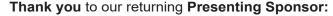


# SAVE THE DATE!



Sunday, May 5, 2019 in Halifax & Sydney and Thursday, May 9, 2019

in Truro & Annapolis Valley





# Participating in Research

By Wenda MacDonald, ASNS Research Liaison and Manager, Client Services

Through the generosity of donors, the Alzheimer Society of Nova Scotia is able to support research both locally and nationally. Another one of the ways we do that is to try to link researchers who need study participants, with people who might want to participate in research studies. By the time you see ads, like the two in this In the Loop, or on any of our sites such as our website or social media, the Alzheimer Society Research Advisory Committee has already met to review the requests and ensure the studies meet a very strict set of criteria, including internationally recognized ethical guidelines. The Research Advisory Committee is comprised of our Research Liaison, our Executive Director, and a number of highly regarded Nova Scotian researchers representing various aspects related to dementia research.

If you have any questions about participating in research, or if you are a researcher and would like to know more about recruitment through the society, please call 902-422-7961 and ask for Wenda.



# Living and Dying with dementia:

# Let's talk about it!

anew study targeting INFORMAL CAREGIVERS of persons living with dementia throughout Canada is underway.

You are invited to take part in the first nationwide study on Informal Caregivers' Attitudes toward Extending Medical Assistance in Dying to Patients with Dementia.

Your opinion on this delicate issue is crucial. All resulting findings will help determine how society should respond to patients with dementia or to their families asking for assistance in dying.

The study investigates the beliefs underlying **informal caregivers' attitudes** on this issue, the **value** they attach to proposed safeguards as well as assessing caregivers' burden and unmet support needs.

The study is led by Prof. GINA BRAVO, PhD, from the Université de Sherbrooke.

Coinvestigators: MARCEL ARCAND, MD, MSc (Université de Sherbrooke, Quebec)

JOCELYN DOWNIE, SJD (Dalhousie University, Nova Scotia)

SHARON KAASALAINEN, RN, PhD (McMaster University, Ontario)

International CEES HERTOGH, MD, PhD (Vrije Universiteit Medical Center, Amsterdam,

collaborators: The Netherlands)

**SOPHIE PAUTEX**, MD (Geneva University Hospital, Geneva, Switzerland)

LIEVE VAN DEN BLOCK, PhD (Vrije U niversiteit Brussel, Belgium)

CONTACT INFORMATION FOR RECRUITMENT SUPPORT

ALINA RUTA, MA Research Assistant RESEARCH CENTRE ON AGING, Room 4410 1036, SOUTH BELVEDERE ST., SHERBROOKE QC J1H 4C4





# Are you or have you been a caregiver? We need your help!

Who? A team of researchers (Principal Investigators: <u>Jennifer Boger</u> and <u>Frank Rudzicz</u>) at University of Waterloo, University of Toronto, and University Health Network are creating a new online search tool, CARE-RATE. CARE-RATE connects family caregivers of people living with dementia with the information, resources, and products they need to support themselves and their care partner. We are looking for all types of caregivers (e.g., family, friends, professionals, etc.) living in the community to participate.

What? We need your expert input! For CARE-RATE to do good searches, we need caregivers in the community to tell us what they think of information on webpages. The opinions of people like you will be used by CARE-RATE to learn how to identify what it's looking for when it does a search.

**How?** We will be using an online tool called *Figure Eight* to collect this data. If you choose to participate, you will be asked to answer questions about webpages (such as a page from the Alzheimer Society) and answer the questions through *Figure Eight*; this will label or "tag" the content of the webpages. **We will use the information collected by** *Figure Eight* **to train the machine learning model that is used by CARE-RATE. No personal information will be collected from you during the rating task.** 

Why? Caregivers are the experts; you have the real-world, hands-on experience that we need. We want to make sure that the information CARE-RATE uses makes sense to caregivers, which means we want caregivers to tell us what they see and think of different websites. Having caregivers label the pages (instead of researchers or people from the public at large) will result in CARE-RATE learning how caregivers perceive, understand, and interpret online information, which means CARE-RATE is more likely to give answers that align with caregivers needs and expectations. We want CARE-RATE to be created by caregivers for caregivers.

Where and When? Online, at any time. You will be asked to label two webpages at a time and can always log off and log back on again at some other time to complete another pair of webpages. This is an open task, you can help as little or as much as works for you, at a time convenient to you; the more you help, the better CARE-RATE search results become.

### Interested in participating?

Please use this link to access the rating task on Figure Eight: <a href="https://tinyurl.com/rating-task">https://tinyurl.com/rating-task</a> The first time you visit Figure Eight you will need to create a new account using your email address of choice and verify your account by checking the email you used to create it.

Questions? Contact: care.rate@uwaterloo.ca

Please pass this flyer along to anyone who may be interested!

NOTE: All information provided by you will be treated as private and safeguarded by all reasonable means. No information will be shared with any third party.











# Sharing the Journey of dementia over Breakfast Get your Alzheimer Awareness Breakfast tickets today!

Before you set out on any journey it is important to be informed and know where you are going, who can help, and to meet great people along the way who can make the journey better. **The journey with dementia is no different.** 

"When we come together we learn we are not alone in the journey with dementia," says Catherine Shepherd, Coordinator of Outreach & Education, Cape Breton. "There are supports and resources in our community that can help with each step of the way. The awareness breakfast lets us learn together, share together and support each other."

Sydney, Cape Breton, will once again host this popular community event. Catherine and committee will ensure that the audience leaves with a better understanding of what life is like on the island for people with dementia.



This January there are three opportunities to join us and share the journey. Alzheimer Awareness Breakfasts details are below and tickets can be purchased by calling the Society at 1-800-611-6345, online at <a href="https://www.alzheimer.ca/ns">www.alzheimer.ca/ns</a>.

**Sydney:** Wednesday, January 16 7:00 a.m. – 9:00 a.m.

Membertou Trade & Convention Centre

Speakers: Rev. Faye Forbes, living with dementia

Dr. Arlene Kelly-Wiggins, CBDHA Geriatric Clinic

Darlene Carey, Caregiver

Bridgewater: Friday, January 25 8:00 a.m. – 10:00 a.m.

The Best Western Plus Bridgewater

**Speakers**: Lynn Slack, Continuing Care Coordinator

Sue Sheppard-Jackman, Geriatric Nurse

Halifax: Tuesday, January 29 7:00 a.m. – 9:00 a.m.

Casino Nova Scotia - Schooner Room

**Speakers:** Sandra Britten, living with dementia

Dr. Melissa Andrew, Geriatric Medicine

Paige Morrissey, Music Therapist



# **Meet Carol & Roy**

**By ASNS staff** 

Carol has a goal: she wants you — and others - to know is that she is still just a normal person. She is still Carol, even after her dementia diagnosis.

As a military wife and mother of four, Carol knows about strength, resilience and getting things done. She didn't want this diagnosis to disrupt her life, but it did. Changes came when Carol couldn't do the same tasks she always had. Her husband Roy had to step in as caregiver. For a couple who has enjoyed a long marriage with very defined roles, this was a big shift for them. Carol and Roy needed help, so they contacted the Alzheimer Society.

Donate now so that we can continue helping couples like Carol and Roy.



Carol & Roy

"Roy and I wanted to learn more about this disease and the impact it would have on our lives. We attended the six week *Shaping the Journey* program offered by the Society. The facilitators were kind, knowledgeable and blessed with empathy. Being part of that program was a very positive experience."

Shaping the Journey is just one of many programs offered by the Society to people with dementia and their partners in care. For these programs to continue and for people to continue to receive the support they need, we need your help.

Roy explains his experience with *Shaping the Journey*, "Being with other people going through the same thing as us was very comforting. Being able to talk to people about what we were experiencing and having them relate was incredible."

"We learned a valuable lesson from our friends at *Shaping the Journey:* it is not how many more years in our life we have left, but how much life is in our years. And with that in mind we live one day at a time and deal with issues as they come, not worry about what might happen."

Carol is a shy person who does not enjoy the spotlight. But her experience with the Alzheimer Society of Nova Scotia was so positive that she felt the need to share her story and hopefully help others experiencing the same journey.

Give now through the form on the next page and with the enclosed envelope, so that Carol can realize her goal of helping others who have been diagnosed with dementia. In the Loop Fall 2018

# Société Alzheimer Society

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