

The Beacon

Fall 2019/Winter 2020

Volume #13



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The Power of Learning Circles

Twice each year the entire Caregivers Nova Scotia (CNS) staff from across the province comes together for three days to review our work, discuss our workplans, and bond as a team. We invite guest speakers and we also have tours of interesting places – organizations and their services that may be of interest to caregivers.

In June we visited the newly opened Hospice Halifax. This 10-bed state of the art hospice provides excellent end-of-life care. The CNS team also met with Horizons Community Development Associates to provide input on Nova Scotia's Direct Benefits such as the Caregiver Benefit, the Supportive Care program, and the Self-Managed Care program. These programs are currently under review by the province and CNS passed along comments heard from caregivers.

In November we sat down with Susan Stevens, Senior Director of Continuing Care for the Nova Scotia Health Authority. It was a valuable discussion for everyone. Many questions were answered and ideas explored. Susan emphasized the value of caregivers to the healthcare system, their families, and most importantly their loved ones.

We also had a fascinating tour of the Maritime Brain Tissue Bank which plays an important role in research into dementia, ALS, MS, Parkinson's, and other neurodegenerative diseases.

Next month we will launch a new section on our website that includes lessons from both Learning Circles. Stay tuned and all the best in 2020.

Angus Campbell
Executive Director



Thank you to the
Department of Health
& Wellness
- Continuing Care Branch
for their ongoing support.



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Introducing New Team Members

Catherine Parent

I'm filled with excitement to have joined the Caregivers NS team as the Caregiver Support Coordinator for the Eastern HRM Region.



When I was growing up at home, I recall family members caring for other members of our extended family. This was our normal. It was the way my family chose to raise us. I clearly remember as a very young child caring for and nursing my dolls and enjoying those moments immensely. My career choices and pathways should never have surprised me!

At the beginning of my career, I was an Early Childhood Educator. This was followed by nineteen years nursing in long term care. This is the path that has brought me to the role of Caregiver Support Coordinator.

The professional side of my life has focused on educating, supporting, and assisting others. Sharing others' lives from a young age through to their later and final years of their lives has offered me the gift of caring.

The personal side of my life has been just as rewarding. Loving and caring for my son who was ill while in his infancy, walking beside my mother while she pushed through her journey with Breast Cancer, being a caregiver to a close friend—each of these experiences has influenced and formed the life I live.

Caregiving is both a trait and a role that many of us possess and share. It is not always easy and it is not always recognized, but it sure is what connects us all within communities and builds our strengths!

The opportunity of being a Caregiver Support Coordinator is a great one. I look forward to enhancing services in Eastern HRM as well as getting to meet and assist the ever growing number of caregivers in our communities.

Working with a great team of knowledgeable people, meeting amazingly strong caregivers, and having a wonderful family in my life make life's journeys worth so much. I can truly say, I am blessed.

I extend an invitation to you to contact me to learn about our Programs and Services and about the assistance and support that we can offer. I look forward to meeting many more family and friend caregivers along the way.

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Therese Henman-Phillips

I want to take a moment to introduce myself as one of the newest members of the Caregivers Nova Scotia team.

In late September 2019, I accepted a 6 month contract with CNS in the role of Outreach Coordinator with special responsibility for identifying the needs for our services of groups within the province who are currently underserved.



Coming from a 35 year career working with families and children, joining an organization that supported family and friend caregivers was high on my post retirement priority list. This was particularly important both because of my general interest as a social worker in caregiving but also as a result of my personal experiences in my own family of origin.

What caregivers do in any capacity is an enormously valuable resource for our province generally and more specifically for our families. I am proud to be a member of the CNS team. I have been amazed in my short time here at CNS of the wonderful staff, resources, and the good work being done to support our caregiving community throughout the province.

My role at Caregivers Nova Scotia is a special project. Our services are available to anyone in the province who is a family or friend caregiver and who wishes to access them. We recognize, however, that the "one size fits all approach" is not always appropriate.

During our work, we sometimes have contact with members of various communities who express an interest in having a service that addresses the unique makeup of our diverse population here in the province. Caregivers and care recipients are influenced by their culture, be that their ethnicity or a shared affiliation and identity that they share. We have identified several such populations as a result of previous work, and we are striving through this project to improve our competence when supporting them.

Initially I will be learning from these populations about what their needs are and how we can better serve them. While it is still only early days, it is our hope that our service can continue to deliver as we have been doing in the past but with a view to improving our service so that we are inclusive and responsive to the unique needs of our caregivers and their care recipients.

Over the upcoming months, we hope we will have more to share as the project develops. Stay tuned!

New Team Member

Jenny Theriault

I joined Caregivers Nova Scotia in September as the new Operations Coordinator. For the past few months I have been thoroughly enjoying learning all the ins and outs involved in this role.

My education is in Gerontology from Mount Saint Vincent University, and I worked for 12 years at VON in Community Support Services. I held a number of different roles over the time I was at VON, but largely worked coordinating Adult Day Programs across Halifax Regional Municipality. In that role I worked extensively with care recipients and also got to know many caregivers and hear their stories and experiences.

Among my roles as the Operations Coordinator, I am responsible for updating our social media accounts. If you aren't already aware, Caregivers Nova Scotia can be found on Facebook ([@CaregiversNS](#)) and Twitter ([@CaregiversNS](#)). Regular updates are posted daily on each of our social media sites.

We promote all workshops that we have scheduled across the province as well as any other events. We also share events relevant to caregivers that other organizations are hosting. We also promote and share interesting articles, educational



opportunities, new research, and reminders about programs or services available to caregivers, and so much more.

As it has evolved over the last 10+ years, Social Media has become an important outlet for organizations, businesses, and individuals. Today social media is a wonderful tool that can be used, for example, to connect individuals to organizations for services, resources, and supports.

Social Media is a tool we at CNS use to reach more Nova Scotian caregivers to share what we do and to promote meaningful and applicable events that might be of interest to caregivers, service providers, and other organizations that follow us on social media. We work hard to post only information and events that we feel might matter, help, or be of interest to caregivers across the province.

We would love for you to check us out on Facebook or Twitter, and to like, share, or follow our accounts. It all helps us reach our organizational goals to offer programs, services, information, and advocacy to caregivers across the province.



If you would like to receive a colour copy of our newsletter by email, please subscribe by going to our website at www.CaregiversNS.org and sign up at the bottom of any page.

War Cake Contributed by Catherine Parent

INGREDIENTS

2 cups (500 ml) dark brown sugar
2 cups (500 ml) boiling water
2 tbsp (30 ml) shortening
1 tsp (5 ml) cinnamon
1 tsp (5 ml) nutmeg
1/2 tsp (2.5 ml) cloves
1/2 tsp (2.5 ml) ginger
1 lb (450 g) raisins
1/2 lb (225 g) chopped walnuts and/or almonds (optional)
3 cups (750 ml) flour
1 tsp (5 ml) baking soda dissolved in 1 tsp (5ml) hot water

Note: This recipe originated and was used during 'war' or 'hard times' as it is a recipe that required inexpensive ingredients that would be likely to be available.

Preheat the oven to 350 F (180 Celsius).
Grease and flour two loaf pans, a tube pan, or a rectangular cake pan.

METHOD

1. Boil together all ingredients except the flour and soda in water, for 5 minutes. Set aside to cool completely. Stir this mixture often.
2. When cool, gradually mix in the flour and soda. This batter will be thick.
3. Pour the batter into two prepared pan(s).
4. Bake in a 350 F (180 C) oven for 45 minutes or until a tooth pick inserted near the centre comes out clean.
5. Remove the loaves/cake from the pan(s) and let cool on a cooling rack.



Winter Preparations

by Brenda Sangster



Winter is fast approaching, and as caregivers we may have concerns about our loved one's ability to navigate the challenges of the season. Falls are always a concern but especially when going outside in the winter. Here are few safety tips to consider.

1. Make sure all railings and steps are in good repair and cleared of snow. Use salt or sand regularly, and have extra on hand throughout the season. Keep driveways, sidewalks, walkways, and mailboxes cleared of snow, ice, and slush, and use sand/salt liberally.
2. Wear proper footwear for the conditions and consider using a cane with a pick (especially in icy conditions). When using mobility aids outside, look for grippers for shoes/boots.
3. If you and the person you are caring for are driving, make sure your vehicle is winter ready (e.g., oil changes, good winter tires, battery, extra windshield wiper fluid, snowbrush).
4. Make sure you have a winter emergency kit in the vehicle. Items to include in a winter emergency car kit are: first aid supplies, water and non-perishable food, blankets, extra clothes, change of footwear, shovel, cat litter or sand, a flashlight, batteries, road flares, heat packets, emergency phone battery charger, waterproof matches and candles, swiss army knife, jumper cables, and rope.

Winter may also be a good time to assess if the person you are caring for is safe and comfortable driving in less than desirable conditions.

It's also a good idea to have a winter emergency kit for the household in the event of a power outage. Items to include in a household winter emergency kit are: water, food (non-perishable), cash, manual can opener, at least one week's supply of medication(s), baby needs, extra glasses, important family documents (e.g., copies of birth and marriage certificates, passports, licenses, wills, land deeds, and insurance), a copy of your emergency exit plan, crank or battery-operated flashlight and radio, extra batteries, extra keys for your house and car, a first aid kit, personal hygiene items, pet food and medication, and a cell phone with extra charger or battery pack.

Automatic delivery of heating oil can help ensure you never run out. The Heating Assistance Rebate Program (HARP) helps low-income Nova Scotians with the cost of home heating. Rebates range from \$100 to \$200. To learn more visit: <http://bit.ly/2XSLSw8>

If you or a loved one are house-bound and need support, there are mobile resources available such as bloodwork, meal or grocery delivery, footcare, etc. Call us here at Caregivers Nova Scotia at 1.877.488.7390 or visit our website at www.CaregiversNS.org for a list of those and other resources.

Assertiveness in Caregiving: Is This Possible?

by Lynn Butler

If you are a family or friend caregiver, how can you be assertive without being aggressive? How do you handle things if the person to whom you give care is rude to you? What if the person you give care to is aggressive, mean, or just takes you for granted? Should you stand up for yourself or just continue to accept the bad behaviour?

This is a very perplexing place to be. If you had a loved one who was doing what you do (giving care) and they told you they were being subjected to unacceptable and hurtful behaviour, what would you tell them to do?

Let's take a look first at what being assertive means and then at ways we can be more assertive in our everyday caregiving role.

Here is one definition of assertiveness from [SkillsYouNeed.com](https://www.skillsyouneed.com). "Assertiveness is the ability to stand up for yourself and your rights, while also protecting the rights and opinions of others." Being assertive in a pos-

itive way can help a person maintain their own identity while at the same time helping your relationships thrive.

Wouldn't it be great to be able to express yourself without becoming upset or upsetting others? Here are some ways, suggested by [SkillsYouNeed.com](https://www.skillsyouneed.com), that you can use assertiveness in your relationships to help manage potentially unacceptable or disagreeable encounters.

Talk openly and honestly about your feelings. Don't let negative thoughts or feelings stay bottled up. The sooner you start opening up and expressing yourself, putting a name to your feelings (sad, hurt, angry, afraid etc.) when they arise, the easier this gets.

Listen intently, doing your best to understand what your loved one, the care recipient, is really telling you. Repeat what you hear and make sure it is what is being said. Try to listen without judgement. Just listen to understand what your person is trying to communicate.

Be grateful when something is done for you, no matter how small. Saying please and thank-you goes a long way and, hopefully, this will become a pattern that gets reciprocated. If you have been taken for granted, you know how badly that makes you feel. Do the opposite. Show by example.

Admit when a mistake is yours and give an apology. This is not easy to do especially if communication is difficult, but an apology can clear the air immediately when given in earnest. This one might be difficult for your care recipient to demonstrate, but over time it may become the new norm.

Share responsibilities when possible. You are both in this together. When possible ask for your loved one's input and opinions. Everyone needs and wants to feel like they have a purpose and that they matter, so treat your person as equal.

Being more assertive is not about being more aggressive. It's about standing up for yourself in the effort to make your relationships better. It's all about respect in the end.



Holding Space

by Jennine Wilson

In the last newsletter I mentioned the privilege I sometimes have of witnessing how people “hold space” for each other in Support Groups. Let’s look a little deeper at what holding space for one another means. Holding space to me is a felt experience, whether you are the one holding space or the one receiving it. As a way of trying to explain, I’ll share a time when I had space unexpectedly held for me.

I was back living in my parents’ home, serving as my father’s primary caregiver. Paid care providers had finally started coming into the home to help and, for the first time in quite a while, I felt able to take the opportunity to get out and do something to care for myself. It had been years since I had lived in my home town. No longer having a base of friends there, I chose some practical self-care. I booked a dental checkup for the first time in years.

I always hated going to the dentist—my brothers never had cavities and I always did. The dentist was the same one I’d seen as a teenager. He also knew my father well and was aware that he was very ill.

Ten minutes after I lay back in the dental chair, mouth wide open, to my surprise tears started to flow from my eyes. The dentist asked if he was hurting me and I shook my head no. It was the way he asked the question, gentle and knowing, and how he held my eyes for a moment before continuing with his work, that allowed me to stay with what was happening. I did not feel the need to put up my defenses, feeling safe to just be and let the tears

fall. The dentist finished his work, put his hand on my shoulder and held my eyes for a moment again before going on to his next patient.

His assistant stayed with me for a moment. I expressed to her my surprise at realizing that was the first quiet moment I had had in a long time and what a gift it was to feel OK to let the tears go. Who would have thought the dentist would be a good place to cry? We laughed, and she said to stay as long as I needed.

What I felt in that office was a sense of being safe and not judged, of being virtually held by people who did not feel the need to fix it or change my way of being in that moment. The dentist and his assistant were both comfortable witnessing my struggle. They did not turn away from my suffering. They faced it and sat with it, which was truly a gift.

Researcher and storyteller Brené Brown says, “When we are looking for compassion, we need someone who is deeply rooted, is able to bend, and most of all, embraces us for our strengths and struggles.”

In practice, to hold space for another we need to be present to ourselves, acknowledge any discomfort we might feel, breathe, ground, and give ourselves the courage to turn towards a person’s struggle. We do not need to internalize it but rather to listen and pay witness to it. We need to suspend judgement and accept the person’s truth at that moment and allow them to just be without needing to fix it.





Jennifer's Picks: A Booklist for Caregivers

by Jennifer Briand

There is almost always a learning curve that people face as they start their journey as a caregiver. They are often concerned they don't have the knowledge, experience, or skills that health care providers possess.

Sometimes the first step towards acquiring the understanding they want and need is by learning as much as you can about your loved one's illness or disability. At our support groups, we often discuss a book or paper that has helped someone better understand their care recipient's situation and how to care for them more effectively.

I have compiled a short list of disease specific books I have read and have personally found helpful. Many of them I have also lent to others. I hope that this list will help you along your journey.

Note: I have listed several books by Lisa Genova. This author has a PhD in neuroscience, and she writes with knowledge and empathy regarding many neurological conditions. Her fiction novels (F) are usually written in the first person, and they provide insight into a disease that will help inform readers of what may lie ahead. The nonfiction books below are marked (NF).

My hope is that this list will help you learn and move forward with understanding.

Please note that these titles are only suggestions from books I've read. There are many others resources available. If you have any suggestions that you would like to share, please contact me at Western@CaregiversNS.org.

ADHD and Autism

- *Right Brained children in a Left Brained World*. Jeffrey Freed & Laurie Parsons (NF)
- *The Curious Incident of the Dog in the Night-time*. Mark Haddon (F)
- *Love Anthony*. Lisa Genova (F)

ALS

- *Every note Played*. Lisa Genova (F)

Brain Injury

- *Left Neglected*. Lisa Genova (F)

Cancer

- *Being Mortal*. Atul Gawande (NF)
- *The Fault in our Stars*. John Green (F)
- *Everything Happens for a Reason and Other Lies I've Loved*. Kate Bowler (NF)

Dementia

- *The 36-Hour Day*. Nancy L Mace & Peter V. Rabins (NF)
- *Still Alice*. Lisa Genova (F)

General Health and Wellness

- *Being Mortal*. Atul Gawande (NF).
This is a great learning tool for health care providers, patients, and caregivers.

Huntington's

- *Inside the O'Briens*. Lisa Genova (F)

Mental Health

- *Turtles all the Way Down*. John Green (F)

Palliative and End of Life

- *Dying, Death, and Wisdom in an Age of Denial*. Kathryn Mannix (NF)
- *When Breath Becomes Air*. Dr. Paul Kalanithi (NF)

A Day In The Life of A Caregiver

By Maggie Roach-Ganaway

Janet lets the phone go to voice message as she is trying to get breakfast on the table for her husband after a busy morning of getting him up and ready for the day. Today is appointment day, so it started earlier than normal. Her husband's dementia is progressing; the medication he was prescribed doesn't seem to be working for him and in fact it is causing side effects that she is concerned about. After the appointment, she will need to stop by the bank to deal with an issue that came up and duck into the grocery store to pick up a few things.

This is just one day in the life of a caregiver and, although every caregiving journey is different, quite similar emotions and challenges come into most of their everyday lives.

A caregiver lives each day wondering what will lie ahead and just trying to get through another day without a catastrophe that may turn their life upside down. For the most part, each day becomes like the last and things gradually seem to become routine and normal.

What most caregivers don't understand is that this sense that things are normal is often a coping mechanism. Underneath, they are seeking their old life back, before they became a caregiver. Most caregivers will not admit this out loud for fear that other people will think ill of them or will think they may be resentful of the situation. But, what caregivers need to realize, is that others feel the same way as well, and that it is normal to feel this way.

Along with making sure personal care, meal prep, house-keeping, errands, appointments, and financial matters

are all taken care of, some caregivers also have to take over the things that their loved one usually took care of. This can be an added strain on the relationship and can lead to those feelings of resentment.

How people handle these feelings is a totally personal thing. But there may be some things they can try to help make it a better place for them.

Taking time for yourself and doing something that gives you joy and pleasure can take your mind off of the everyday "tasks" that have to be done.

Joining a group whether it is a support group or a line dancing group will give you a chance to talk with other people and break up the monotony of everyday life.

Writing down your feelings in a journal may help you get some feelings out that you may not be able to tell anyone else and this can act as a release for some people.

Getting organized and writing things down, will help with things that pop up at the last minute and make them easier to deal with.

Planning ahead for things that will need to be dealt with in the future, may ease your mind about what the future may hold.

These things shouldn't feel like just another chore that has to be completed. They are meant to act as a distraction and an enjoyable interlude in the everyday routine that has become your life. Make everyday a time to cherish instead of dwelling on the negative things that you have no control over.



Wishing you a peaceful and
joyous holiday season.
All the best for a
wonderful 2020.