

The Beacon

Spring and Summer 2023

Volume #17, Issue 1



In This Issue

The Art of Siblings	2
Caregiver Voices	3
Tips for Virtual Care	4
Trust	4
Welcome Lyn Stuart	5
Nurtured by Nature	6
The Caregiving Dance	7
La danse des aidants	8

Board of Directors

Executive Officers

Patricia Murray - Chair

Ruvi Nora Magara
- Vice-Chair

Mary Elizabeth MacLellan
- Treasurer

Anne Corbin - Secretary

Members at Large

Sherri Mitchell

Paula Blackmore

Kelli MacDonald

Catherine Morley

Kimberley Chretien

Nancy Day

Brittany Keough

Wendy Menczel


Caregivers
Nova Scotia
for friends and family giving care

3433 Dutch Village Road
Halifax, NS B3N 2S7

Tel. 902.421.7390

Toll-free 1.877.488.7390

Info@CaregiversNS.org

www.CaregiversNS.org


NOVA SCOTIA
CANADA

Thank you to the
Department of Seniors
and Long-term Care
for their support

Hello Caregivers, Community Partners and Friends,

I'd like to start by recognizing that May is Caregiver Awareness Month. We are continually in awe of all that caregivers do every day for those they are caring for, with no compensation and little recognition. We at Caregivers Nova Scotia, see you, recognize your value and contributions, and want to give our deepest heartfelt thanks to each one of you. Thank you, Caregivers!

Work continues on our two projects funded by the NS Department of Seniors and LTC via the Nova Scotia Centre on Aging. We are thrilled with all the hard work and effort they (NSCA) have put into these projects – A review of caregiver training/education and A Strategic review of family/friend caregiving in Nova Scotia. These projects will finish in summer of 2023. We also want to acknowledge and thank all those caregivers and partners who participated in focus groups and surveys. Your feedback is crucial and greatly appreciated.

We welcomed Lyn Stuart, Caregiver Support

Coordinator, Cape Breton to our team (learn more on page 5) at the end of 2022 and love her energy, drive, and compassion for caregivers. She is already making her mark and we anticipate continued great things for caregivers in Cape Breton!

We also said goodbye to Catherine Parent, Caregiver Support Coordinator, Eastern HRM. Catherine built up our caregiver support in Eastern HRM and has worked hard to build a presence and rapport with caregivers on the eastern shore. We are grateful for all her contributions to our organization and team. We wish her the very best in all her future adventures.

Caregivers Nova Scotia was invited to Province House on April 4th to be recognized on National Caregiving Day. We were honoured to be invited and for caregivers to be recognized.

Jenny Theriault
Executive Director



MEMBERS OF CAREGIVERS NOVA SCOTIA WITH PREMIER TIM HOUSTON AT PROVINCE HOUSE ON APRIL 4TH ON NATIONAL CAREGIVING DAY.



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.



Got Feedback?

We're listening. Give opinions
and provide feedback on
services, newsletter, programs,
... everything CNS.

Please contact us.
1.877.488.7390
or www.CaregiversNS.org

The Art of Siblings

Therese Henman-Phillips, Caregiver Support Coordinator, Capital Region

There were no navigation charts for this journey. When my father became ill, as siblings, we rallied. There were definitely bumps, tension, strain and loss. Our new role as caregivers, quickly changed the sibling equilibrium established as adults. At times, I asked my mother why she didn't have more children, thinking the more bodies the better and at other times I thought some things would be easier if I was an only child, needing no opinions or consensus.

At CNS, we understand that caregivers are a special breed, but we also need to remember that not everyone is a caregiver, even those raised in the same family. Maybe your sibling has challenges themselves, physical or mental health issues, a young family or an extremely stressful job. Maybe they live out of province. These things are not going to change to support the current family crisis. Expecting that they will be able to equally contribute to the caregiving role is our first mistake. The division of labour isn't always fair.

The roles that define a caregiver however can be very broad. Are there roles where they can be useful? Don't assume because they are your siblings, that they have insight. Have a list of duties available and let them choose something that they can be successful at. Be clear on expectations.

Family communication is vital. Communication is important to convey the direction of care, to assess whether or not everyone is on the same page, to convey why certain supports are needed and to ask for help with specific tasks. With today's technology, it is very easy to set up some methods. Hopefully consensus can be reached, but sometimes, due to either trust that has been imparted, availability or an assigned legal role, someone is ultimately leading the decision making. It is still important to keep everyone informed. Making everyone feel part of the team can encourage ongoing respect and future participation.

Caregiving is a highly emotional role and we all have a unique family history as siblings. Keep in mind that your parents may be struggling as well with memory issues and conveying things differently to each adult child. Don't involve others in the conflicts that may occur by playing siblings off against the other or parents. You need to guard against those negative emotions that can alter relationships and could remain strained long past the end of your caregiving role. Try to start each day with a clean slate. A coworker's favorite saying- QTIP- "quit taking it personally". A lot of what is happening in some situations, is unique to the demands of caregiving.

As good as you are in your caregiving role, don't expect everyone in your family to be like you. "Good enough" verses optimal is ok. I know that's hard to hear when parents are involved. If you are feeling overburdened, the onus is on you to care for yourself. If upset by the lack of equality, take a step back, calm yourself and look at other ways things can be accomplished with the use of outside support or other resources. You have to remember this is also affecting your

own family responsibilities and those dynamics may exist long after the role has ended.

Caregiving can be very life enriching but when the challenges become too difficult for families, there are resources that can help siblings sort through the storm - support groups, mediation and senior care consultants to name a few. Many families find it useful to have someone look at the situation with fresh eyes.

If you are a sibling that is limited in the role you are able to support, make sure to acknowledge those who are taking on the bulk of the workload. A simple thank you or small gesture can go a long way to making your siblings feel appreciated. Acknowledging sacrifice is important.

Most of all on our sibling journey, keep compassion in your hearts. It is always the best anchor in stormy seas and the best chance at preserving those enduring sibling relationships.



Caregivers Voices: For Community Awareness

Jennine Wilson, Caregiver Support Coordinator, Valley Region (Annapolis, Kings and West Hants counties)

May is Caregiver Awareness Month. I asked Caregivers what they would like their communities to be aware of when it comes to the caregiving journey.

"It is after the fact now and I would not have given up that journey for love or money. In the throes of it all there were many days I wanted to give it up. Caregiving is isolating and your world can become very small. Little moments become precious amongst the mountain of moments of fear, grief, frustration and feeling like no one else cares, not even the professionals."

"I never expected this to happen. There have been a variety of serious medical conditions, but we never had to deal with a diagnosis like this one. It has been a big learning curve, and I have had some difficulty in asking for help. I am a very private, introverted person, and this requires me to reach out, and ask for help. I often feel inadequate, and don't think I am doing a good job. I wish I had more help, someone to really understand this, and what the future looks like. If I look at them and really think about how they used to be, it is so heartbreaking, so I don't do that. I have to take it one day or even one hour at a time. I think most of us are just trying our best to cope."

"You need to consider self-preservation when caregiving as you can quickly burn out, you need to consider yourself and your own self-care."

"Caregiving is a huge but necessary commitment on the part of the caregiver when dealing with dementia. It is important for me to arm myself with knowledge of the disease with which our loved one has been diagnosed with, as there are many different forms of dementia. As a caregiver one cannot fix the problem, therefore one must stay on the outside of the problem so you can be a good caregiver, not easy but necessary to maintain your mental health. Always seek self-care either through support groups where there are common

thoughts or privately for personal care."

"Please do not say it is a really good thing you are doing, pat me on the back and say, let me know if I can help, unless you mean it!"

"I don't need others' advice, sometimes I just need you to put your hand on my shoulder and listen whether I am crying or venting"

"Ask me how I am doing versus asking how my person is doing, means a lot"

"Please do not ask me to do things. I have a hard time saying no and I am already overwhelmed"

"I am sleep deprived and deal with compound stress please be gentle and understanding with me."

"Do not ignore me like I do not matter, am not essential or don't know my people better than anyone."

"Bring a meal, rake my leaves, visit, take them for a drive don't say let me know if I can help, I already have too many things to think about to figure out how you could help. Please, if you see something that could help do it. If I do not seem grateful at first remember it is hard to receive until you get practiced at it."

"Thank you to all the neighbours, businesses, health professionals who do all they can to make it easier. Making things easier in this day and age does not seem to be the norm. I know your efforts have extended my life as a caregiver"

I would like to thank all the caregivers who shared their thoughts. I hope Caregivers NS makes caregivers feel appreciated, heard and contributes to making something feel a bit easier.



Tips for Virtual Care Nova Scotia

Leanne Taylor, Caregiver Support Coordinator, Northern Region

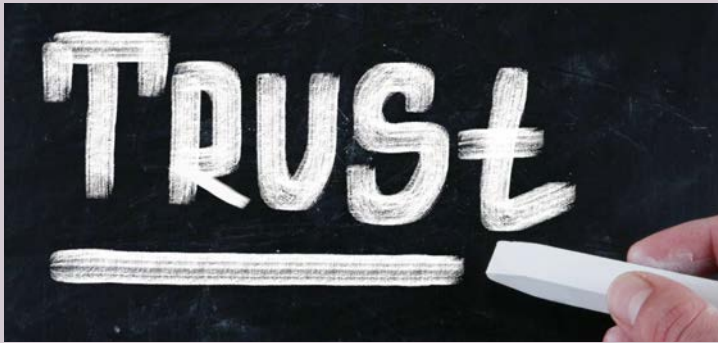
In our winter newsletter, I highlighted the benefits of virtual care for caregivers. In this newsletter, I am sharing tips for using VirtualCareNS. Like many other Nova Scotians, I do not have a family doctor, and utilize VirtualCareNS.

Helpful Tips:

- All residents of Nova Scotia with a MSI Card can use Maple (the app used), but it is only free if you do not have a family doctor. You must be registered with 811.
- After registering with 811, to be added to the list to receive a new family doctor, allow two weeks to receive the email introducing VirtualCareNS. Once you receive the email and make an account, you can meet with a virtual doctor.
- A scanned copy or picture of a government ID and Nova Scotia MSI Card are required, and you will need to download the pictures into the app.
- VirtualCareNS hours of operation are Monday from 9am to 7pm, and Tuesday to Friday from 9am to 5pm.

- Once you have made an account, there are questions to answer with information on your medical history. These include all the medications you are on, allergies, diagnoses of health conditions, surgeries, etc.
- When making an appointment, allow time to check the availability of appointments, and also for time to wait to talk with the doctor.
- If a prescription is needed, the doctor will send the prescription to your pharmacy, but you will first need to accept this on the app before your prescription can be sent to your pharmacy and filled.
- If you require more than the virtual doctor can help with, a referral to the Access Clinic closest to you will be made. Within a month, you will receive a call with two appointments for you. The first appointment will be on the phone to get more history from you, and the second one will be in person at the clinic.

If you need help accessing a virtual doctor, reach out to us at Caregivers Nova Scotia, and we will help you navigate.



Nicole Byers,
Caregiver Support Coordinator, South Shore Region

Trust is a small, five-letter word, but it holds great weight. As a caregiver, it can feel like you are the only one who can do certain tasks. We are often told, "If you want something done right, you have to do it yourself." However, we know that caregivers can't do everything themselves. Sometimes you have to be okay with relinquishing control and allowing someone else to take on some tasks. It may not be done the exact same way you would have done it, but the task will likely still get done. Letting go of some control is a way of trusting another person to do what they say they will do.

Brené Brown is a researcher, author, and lecturer who is known for her work focused on shame, vulnerability, and trust. She paraphrases Charles Feltman's definition of trust as "choosing to make something important to you vulnerable to the actions of someone else." Trusting someone means that you must let yourself be vulnerable. And that isn't easy for many folks. Trust is easily broken and often, not easy to get back. But sometimes, as a caregiver, trust in someone else is not a choice. Sometimes caregivers must trust that someone else will show up. For a caregiver's own wellbeing, trust in others is paramount.

Brené Brown says, trust is like a marble jar; you fill the jar up over time with marbles and when the jar is full of many small acts of kindness, you know you can trust the person. For example, if I ask a friend to meet me somewhere at a certain time and they do, that small action shows me that I can count on them. If I ask that same friend to call me a week later to check in on me and they do, that is another marble in their trust jar. These small demonstrations that someone will be there for you, that they will show up, and do what you need them to do is how trust is built. These small actions, this collection of marbles, will eventually add up to trusting that person; knowing that you can share your deepest fears or desires with them, and feeling confident that this person will keep that between the two of you.

Sometimes you think you can trust someone, but they don't keep your confidence, and that trust is broken. At times, trust can be earned back by adding more marbles to the trust jar, and sometimes people are not able to trust again. That is completely dependent on each person, their personality, and their past experiences with trusting others.

If you consider the small instances where a person has shown up for you and proven that they are dependable, it might be a good sign that you can trust them. There are times when you won't know if you can trust someone until you give them the chance. Sometimes you have to let yourself be vulnerable in order to know if you can fully trust someone. And more often than not it is worth opening up and talking about things. So, start small, be vulnerable, and give someone the chance to prove you can trust them. Because you shouldn't have to do it all alone!

Inspiration for this article

Brené Brown's Anatomy of Trust - BRAVING
Boundaries - Reliability - Accountability - The Vault - Integrity - Non-judgment - Generosity

Thank You, Community Partners!

Caregivers Nova Scotia currently hosts 25 in person support groups across Nova Scotia. We are grateful and indebted to our many generous community partners for the use and donation of space to hold these support groups each month and for the community partners who kindly donate space for workshops and other events.

Find below a list of the kind and generous supporters. We thank you!

South Shore Public Libraries
Queens Place Emera Centre
Our Health Centre
Town of Lunenburg
Tantallon Library
Chebucto Connections
Community Health Team Young Street
Community Health Team Spryfield
Digby Legion
Kingston Library
New Minas Baptist Church
Cedar Centre in Windsor
Berwick District and Lions Club
Greenwood Sobeyes
Digby Library
Kingston United Church
New Beginnings Center
Digby Recreation
Centreville Baptist Church
CORAH Centre for Rural Aging and Health
New Ross Family Resource Center
Glace Bay Library
Town House Glace Bay
Medicine Shoppe Port Hawkesbury



Whitney Pier Pensioners Club
Greenwood United Church Baddeck
Knox Presbyterian Church Baddeck
Inverary Manor
Self Help Connection
Bedford Public Library
Sackville Public Library

Woodlawn Public Library
Cole Harbour Public Library
Community Health Team Dartmouth
Sagewood LTC Home
Northwood Ivany LTC Home
Eastern Shore Memorial Hospital
Sheet Harbour Public Library
Twin Oaks Memorial Hospital
The Old School Gathering Place
Musquodoboit Harbour Public Library
Musquodoboit Valley Family Resource Center
Lake and Shore Recreation Center
East Preston Family Resource Center
Cole Harbour Public Library
RCL - Branch 164 Eastern Passage
RCL - Branch 161 Chezzetcook
RCL - Branch 58 Sheet Harbour
Shubenacadie United Church
Amherst Anglican Christ Parish Hall
Westville Library
People's Place Antigonish Town & County Library
Unity Room with Community Enhancement Association at the Truro Library

Welcome Lyn Stuart - Caregiver Support Coordinator, Cape Breton



I count myself fortunate to be the new Coordinator in Cape Breton. Professionally I have worked as an LPN for over 10 years in both primary and tertiary care.

In my personal life, I have been a caregiver. Paramount to my ability to care for those who are closest to me was

being cared for myself, and solid support systems. In turn, I have cared for them; my father died seven years ago after a battle with cancer and my mother had an emergency hospital

admission that resulted in a long road of recovery.

As well, when both my aunt and my grandmother received a diagnosis of dementia, I assisted in their care and support them as they transitioned from their home to living in Long Term Care.

For me, caregiving has been an experience of giving back to those who have given so much to me in life.

I am honoured to have this role; to be the gentle nudge someone may need towards caring for themselves, or the hand that guides them through the often-choppy waters we all navigate during difficult times.

It truly does take a village in all stages of life – and I am looking forward to meeting more of my community and working together to stay well, empowered, and supported.

Contact Lyn: CapeBreton@CaregiversNS.org | 902.595.0128

Nurtured By Nature

- How We Can Find Relief and Healing in Movement and The Great Outdoors

Lyn Stuart, Caregiver Support Coordinator, Cape Breton

Logically speaking, there are 24 hours in every day. It can also be said that we all don't have the same 24 hours in a day, speaking to individual situations, privilege, and circumstances that some of us face - we all just don't end up with the same amount of that precious free time. When time is granted to us, there is sometimes such a list of to dos, it can feel paralyzing. I'd like to pose a challenge to us all, as our season turns and our days grow longer and our earth wakes up - give yourself 23 and ½ hours a day for the many tasks and obligations, and take 30 minutes each day to move your body and find yourself in nature. I have a passion for accessibility - movement in nature is free, is simple, and can have a long-lasting impact on your well-being.

The benefits of exposing yourself to nature are impressive - like nature itself - it is a true wonder what a forest, a park, a walk along the water, or a simple stroll through your neighborhood can do for body and mind. Time in nature has been found to reduce levels of stress and improve working memory, increase happiness, and give a deeper sense of purpose in life. Similarly, the benefits of exercise have the greatest return for investment than any other form of health maintenance; better than reducing smoking, lowering blood pressure, drinking less - you get the gist. The stark reality; a sedentary lifestyle can take years off your life. Six hours of TV a day equals 5 less years on your life. To flip the script, exercise

has been shown to reduce pain and disability in patients living with knee arthritis by 47% and slow progression of Alzheimer's and Dementia by 50%. Simply put - exercise improves quality of life, and greatly reduces depression and anxiety. The dose? The higher the output, the greater the reward with a goal of 150 minutes per week or 30 minutes almost every day. With acknowledgment that not everyone has a pile of free time lying around, chunking those 30 minutes up into snacks instead of one meal works, too! Ten minutes 3 times a day will give you those same benefits.



Try and take the time to get to know whatever bit of nature is around you. Take a brisk walk around the block and take in some cleansing breaths of fresh air. Slow down and take in the colours and the many shades of green around you, stare deep into bodies of water, and place your hands or bare feet in the dirt. Surprisingly, it turns out that an ancient bacterium that thrives in soil, *Mycobacterium vaccae* — often referred to as “the old friend” can have similar benefits to you as reducing stress. Maybe this spring, plant some seeds and watch something grow.

In a world that can be rife with difficulty, dedicating just a small fraction of our days to reconnect with nature and move our bodies may just be the balm our brains and bodies need.



PREMIER TIM HOUSTON HAS PROCLAIMED MAY 2023 AS 'CAREGIVERS AWARENESS MONTH'

Donate Today

Caregivers Nova Scotia provides programs, services, and advocacy for caregivers. With ongoing support from our funders, Board of Directors, allied organizations, and caregivers themselves, we're dedicated to providing recognition and practical assistance to friends and family giving care.

**Donate today
by visiting
www.caregiversns.org.**

Registered Charity
No. 87932 1420 RR0002



The Caregiving Dance: Ivan and Sheila's Story

JoAnne Connors, Caregiver Support Coordinator, Capital Region

As caregivers, one of the wonderful yet challenging aspects we must learn to manage is striking a balance between assisting our care recipient and encouraging them to do as much as they can independently. It's akin to a dance where one person traditionally takes the lead and the other follows, but as the care recipient's illness progresses, these roles can shift significantly. This often entails a great deal of negotiation, worry, stress, fear, and grief that must be processed, and as circumstances continue to change, the caregiver's role evolves accordingly.

Ivan and Sheila graciously welcomed us into their home to share their experiences as Sheila lives with progressive Parkinson's Disease and other health issues. Sheila received her diagnosis in 2011, and as many are aware, the process of obtaining a diagnosis can be quite exhausting. It often involves navigating a maze of specialist appointments, tests, and the frustrating phenomenon of medical gaslighting, where individuals are made to feel as if their symptoms are not valid or are all in their head.

After receiving her Parkinson's diagnosis, Sheila took steps to organize her affairs. As a successful businesswoman and teacher, she had been responsible for managing the family finances and supporting the community. Letting go of some of these responsibilities was challenging, and it was initially frustrating for Sheila when Ivan didn't fully understand the extent of her limitations. Ivan continued to work, but it became increasingly clear that he needed to take on a more active role in managing their home life. Eventually, Ivan retired from work to become a full-time caregiver for Sheila and took on tasks that she was no longer able to manage due to her illness.

Sheila and Ivan are surrounded by their two sons and daughter along with 7 granddaughters, which brings them both great joy. The yard and house were beautifully decorated for Easter, and a special family time and egg hunt was scheduled for the weekend. Decorating is something they do together now. Sheila suggests where to put things and Ivan assists. Sheila was used to organizing all of these family events and activities, and Ivan was not. Another thing that they started to do together was cooking.

Sheila did what she could as long as she could, and Ivan supported that. Sheila also says her good relationship with her daughter, an RN, helps them both as well. When she gets scared, she will speak with her. Each family member has a role and they are all very supportive.

During our discussion, Ivan and Sheila both emphasized the importance of good communication and having different people in their support circle take on different roles. Sheila has had to endure many hospital visits, and the most difficult times were during the COVID-19 pandemic when visitors were not allowed. Ivan was designated as Sheila's caregiver and noticed that she was deteriorating in the hospital, leading him to believe that she would be better cared for at home. After discussing this with Sheila, the family, and medical staff, they made the decision to bring her home and provide care in the comfort and safety of their own residence.

Sheila and Ivan try not to dwell on the negative. They still have their moments of disagreement, but in observing them, there is always humour there as well. Ivan has worked very hard learning the things that she likes, and dislikes. That could be bumpy at times, but when Ivan took Sheila's advice and cooked the way she did, he says he learned so much! According to both of them, maintaining a positive mindset is crucial for their success. Despite experiencing health issues and sleep deprivation, they actively choose to remain optimistic.

Ivan also shared that educating himself about Parkinson's Disease was beneficial for him. Joining a Parkinson's Support Group has also been helpful for both him and Sheila. Ivan also attends a Caregiver Support Group with CNS. The journey with Parkinson's has been isolating for them as they were once very active and community-minded people. They miss the sense of connection and social interaction that they once had.

Both Ivan and Sheila emphasized the importance of taking care of their mental health and being kind to each other. Sheila's family has been supportive in helping her find new equipment and tools to make her life easier. They offer suggestions and ideas to help improve her quality of life. Family support has been integral to their mental health, and they are grateful for the love and kindness they receive.

In conclusion, Ivan and Sheila both agree that love is what gets them through the hard times, changes, complications, and learning they have had to face over the last 11 years since Sheila's Parkinson's diagnosis. Though there are moments of sadness, they also find moments of joy and hold onto the love they have for each other and their family.

We express our immense gratitude towards Ivan and Sheila for generously welcoming us into their home, sharing their personal story, showcasing their stunning family photographs, and showing us the precious gifts from their grandchildren. We sincerely appreciate the opportunity to discuss their journey together with them.



SHEILA AND IVAN SHARE A SMILE

La danse des aidants : L'histoire d'Ivan et de Sheila

JoAnne Connors, Coordinatrice du soutien aux aidants, région centrale

En tant qu'aidants, nous apprenons à gérer l'équilibre entre le fait de faire des choses pour notre personne soignée et le fait de l'aider à faire autant qu'elle peut elle-même. L'un de nos aidants a comparé cela à une danse où une personne prend traditionnellement la tête et l'autre suit, mais les rôles peuvent changer considérablement à mesure que la maladie progresse. Nous devons négocier, faire face à l'inquiétude, au stress, à la peur et au chagrin, et notre rôle évolue constamment.

Une fois que Sheila a été informée de son diagnostic de Parkinson, elle a pris soin de ses affaires. Femme d'affaires accomplie et enseignante, elle s'occupait de la famille, des finances et des membres de la communauté. Le fait de devoir relâcher certaines de ces responsabilités a été très difficile et, dans une certaine mesure, frustrant, car Ivan ne « comprenait pas » vraiment au début. Il a continué à travailler, mais il est devenu de plus en plus évident qu'il devait prendre un rôle beaucoup plus participatif à la maison. Finalement, Ivan a pris sa retraite pour être à la maison à plein temps avec Sheila et a pris en charge les tâches qu'elle a dû partiellement ou complètement abandonner à la maison et dans la vie en général.

Cela a été un grand changement pour eux deux, mais ils ont réussi à trouver un nouvel équilibre ensemble. Sheila et Ivan sont entourés de leurs deux fils et de leur fille ainsi que de 7 petites-filles, ce qui leur apporte une grande joie. Leur maison et leur jardin étaient magnifiquement décorés pour Pâques, et un moment familial spécial avec une chasse aux œufs était prévu pour le week-end. Maintenant, ils décochent ensemble. Sheila suggère où mettre les choses et Ivan l'aide. Sheila avait l'habitude d'organiser tous ces événements et activités familiaux, mais Ivan ne le faisait pas. Une autre chose qu'ils ont commencé à faire ensemble est la cuisine. Sheila a fait ce qu'elle pouvait aussi longtemps qu'elle a pu, et Ivan l'a soutenue. C'est très touchant de voir comment la famille est présente pour aider Sheila et Ivan. La relation étroite entre Sheila et sa fille est particulièrement précieuse, car elle peut fournir un soutien émotionnel ainsi que des conseils professionnels en tant qu'infirmière diplômée. Il est important de souligner l'importance de la famille et des amis pour les personnes qui vivent avec une maladie chronique, car cela peut faire une grande différence dans leur qualité de vie et leur bien-être émotionnel.

Cela montre l'importance de la communication ouverte entre les aidants, les personnes soignées, les membres de la famille et les professionnels de la santé. La pandémie de COVID-19 a rendu les choses encore plus difficiles pour les aidants et les personnes soignées, mais grâce à leur communication, leur soutien mutuel et leur créativité, ils ont réussi à surmonter les défis. Les aidants doivent souvent prendre des décisions difficiles en consultation avec leur famille et les professionnels de la santé pour assurer la

sécurité et le bien-être des personnes soignées. Dans le cas de Sheila et Ivan, ils ont réussi à maintenir un environnement sûr et sécurisé pour elle en la ramenant à la maison, où elle a reçu des soins appropriés.

C'est une attitude admirable de la part de Sheila et Ivan de maintenir un état d'esprit positif malgré les défis auxquels ils sont confrontés. Cela peut certainement aider à réduire le stress et à améliorer leur qualité de vie. La communication et l'adaptation des rôles sont également des aspects importants pour maintenir un environnement familial sain et soutenu. Nous pouvons tous apprendre de leur exemple et être plus conscients des défis auxquels les aidants sont confrontés, ainsi que de l'importance de soutenir les personnes atteintes de maladies chroniques et leurs aidants.

Le groupe de soutien leur a offert une communauté de personnes qui comprennent ce qu'ils traversent, et leur a permis de se sentir moins seuls dans leur expérience. Sheila ajoute que la communication avec leur médecin et leur équipe de soins est également importante, car cela leur permet de comprendre ce qui se passe et de savoir comment gérer les différentes phases de la maladie. Elle souligne également l'importance de l'activité physique et de la stimulation cognitive, en particulier pour les personnes atteintes de la maladie de Parkinson.

En fin de compte, Sheila et Ivan veulent que leur expérience serve d'inspiration et de soutien à d'autres familles qui traversent une situation similaire. Ils insistent sur le fait que la communication, l'optimisme et la recherche de soutien sont des éléments clés pour surmonter les obstacles et profiter de la vie malgré les défis.

Ils ont tous deux souligné l'importance de prendre soin de leur santé mentale et d'être bienveillants l'un envers l'autre. Lorsque Sheila a besoin d'un nouvel équipement pour lui faciliter la vie, sa famille lui fait part de toutes sortes de suggestions et d'idées. Le soutien familial fait partie intégrante de leur santé mentale.

Enfin, ils ont mentionné que l'amour leur permettait de tout surmonter. Les moments difficiles, les changements, les complications et l'apprentissage qu'ils ont tous deux dû faire au cours des 11 dernières années. Il y a des moments de tristesse, mais aussi de joie.

Nous exprimons notre immense gratitude envers Ivan et Sheila pour nous avoir généreusement accueillis chez eux, avoir partagé leur histoire personnelle, avoir mis en valeur leurs superbes photos de famille et nous avoir montré les précieux cadeaux de leurs petits-enfants. Nous apprécions sincèrement l'occasion qui nous a été donnée de discuter avec eux de leur parcours.

Caregivers Nova Scotia acknowledges that we live and work in Mi'kma'ki, the ancestral and unceded lands of the Mi'kmaq People. This territory is governed by the Treaties of Peace and Friendship. We are continually learning more about how to engage and move forward with the work of truth, reconciliation, and equity. We recognize that without action, an acknowledgment is empty. It marks the beginning of the work ahead of us, not the end. We are all treaty people.