# The Beacon

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# Hello caregivers, community partners and friends

May is a special time at Caregivers Nova Scotia when we recognize, celebrate and thank caregivers for all they do during **Caregiver Awareness Month**. Daily we are humbled by the stories we hear from caregivers – sharing challenges, grief and joy. We are forever grateful to be a source of support, information, referrals and education. Our heartfelt thanks to all caregivers, we see you and thank you.

We have a few events scheduled for our Caregiver Awareness Month.

In May and June, we are partnering with Northwood to offer **Artful Connections** – 2-hour in-person creative workshops for dementia caregivers. The workshops will take place in Halifax, Shubenacadie, Dartmouth and Pictou. See our website and social media for more information.

We will also be hosting a **Caregiver Appreciation Tea** on May 27<sup>th</sup> at the St. Andrew's Recreation Centre. Call or email us to register!

In March, we welcomed Tomi Adesina to our team. Tomi is leading our Social Prescription project. We are looking forward to connecting with pharmacies, collaborative healthcare practices and doctors to help identify and support more caregivers in Nova Scotia.

Nicole Byers is returning from parental leave to her position of Caregiver Support Coordinator in the Western region. Sheila Landry, who was filling Nicole's position, will be staying on as a Caregiver Support Coordinator supporting the Social Prescription project.

We are looking forward to a busy, fulfilling year ahead and wish all caregivers, community partners and friends a safe spring

and summer!

Jenny Theriault
Executive Director



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# **Caregivers Nova Scotia**

3433 Dutch Village Road, Halifax, NS, B3N 2S7 902.421.7390

**Toll-free:** 1.877.488.7390

Info@CaregiversNS.org www.CaregiversNS.org



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



# Caregiver profile: A sign for advocacy

by Ana Merkureva

**Photo:** Shirley Hodder (left) with her mom Tracey Gibsor

Timer goes off in an empty kitchen. The smell of cooked – and now slightly burning – food rises up, as baby feet tap across the floor. Shirley Hodder searches for her Deaf parents, who are in another room, unaware it's time to turn off the stove.

Since she was a little girl, Hodder has been a caregiver for her parents. She started advocating for them in a doctor's office and in front of the Labour Board. Today, she advocates for entire communities as the African Nova Scotian Health Services Consultant.

### **Early caregiving**

Hodder grew up in Gibson Woods – a small historic community of Black Loyalists in rural Annapolis Valley. As a child of the only two Deaf people in the community, she quickly became the link between her parents and the larger world.

At first, it was simple. "I'd leave with my mom wherever she went and start interpreting as she signed," Hodder shared. As her vocabulary grew, she entered new spaces: by the time she was "7 or 8", she joined her parents at the bank and dove into the world of chequing accounts, savings, overdrafts and ATMs. A few years later, when her parents' contracts were cut short, she'd rush home from school to make resumes, arrange and interpret at the interviews.

### **Facing barriers**

Interpreting was easy.

Dealing with how some people responded – wasn't.

"There were a lot of things I heard that I didn't tell my parents," Hodder said. "I was softening the tone of voice, phrasing things nicer — a lot of people were very rude." She was also the one who had to deliver painful news: "I'd need to explain why they can't get a job – many times I was told they were a liability and weren't a good fit. I would interpret it to them and see their disappointment."

As Hodder advocated for her parents in front of the Labour Board, she faced another challenge: a school system that misjudged her abilities and needs.

In middle school, without her parents' knowledge or consent, she was placed on an Individual Program Plan (IPP) – a path usually meant for students who needed extra help to get through school.

"I didn't know I was on IPP until Grade 11," Hodder shared.
"I assume, they tried to help me this way, but I didn't need it.
I was an Honours student, I took Chemistry 12, Biology 12, the only thing I didn't have was math." By the time Hodder found out, nursing, the career she once dreamed of, was no longer on the table. So, she picked Health Promotion.

### **Unplanned path**

In hindsight, it was a perfect choice. "I found my passion," she said. "Health promotion is advocacy work, community work, identifying issues with social determinants of health: if you are Black, if you have a disability, if you are in a rural area – how do all of these factors combined affect your wellbeing? How do we come together to address that?"

As a caregiver, she looked from the side at her life, the barriers she spent her life navigating. In class, she gave many examples, trying to let people think what they would do in a similar situation, how they can improve it.

"For example, I'm trying to communicate a very serious health issue to the mother, who is the patient, but there's no interpreter there, so the young daughter is interpreting my words. How do I phrase it to her, making it age-appropriate? Should the family book the interpreter? There can be an emergency, when that's not an option."

### **Driving change**

Over the years, Hodder kept sharing her story to spark change.

One of her first victories came when the Labour, Skills and Immigration Department created an Equity Committee, inspired by her advocacy. Their goal: to identify barriers faced by disabled workers and to improve legislation.

Today, at Nova Scotia Health, Hodder keeps pushing for change. Her calendar is full - back-to-back meetings, evenings, weekends – but she shows up wherever the momentum is strongest: where there are people, resources, funding and the will to act.

"In order to fix a systemic issue," she said, "you need to have a system."

And you need voices willing to speak.

"If I don't say anything, if I don't show up in the spaces I have the privilege to access, nothing is going to change. We advocate, we share, because you never know who's going to be in that room, listening. They could be monumental for that change."



# **Burnout vs. Compassion Fatigue**

### by Lyn Stuart

If you're a caregiver, chances are you've felt completely wiped out at some point — physically, emotionally or both. Maybe you've even wondered: is this burnout? Or something else?

Two of the most common challenges caregivers face are compassion fatigue and caregiver burnout. They can look similar on the surface, but they're not quite the same — and knowing the difference can help you figure out what kind of support you actually need.

### **Compassion fatigue**

Compassion fatigue tends to creep in when you're emotionally drained from caring for others, especially if you're constantly exposed to pain, trauma or suffering. Over time, it can feel like your emotional tank is just...empty.

You might still care deeply, but you may also feel disconnected, numb or even a little cynical. You're emotionally worn down, and it's hard to summon the same level of empathy or patience you used to have.

This isn't about being a bad caregiver it's about being human and needing care yourself. Burnout

Burnout, on the other hand, is usually more physical and mental.

It comes from doing too much, too often, with too little support. It's the result of juggling endless tasks, not getting enough rest and feeling like there's no end in sight.

Burnout might show up as exhaustion, sleep problems, frustration, irritability or a sense of being trapped in your role.

You might find yourself fantasizing about quitting or snapping more easily than usual.

Compassion fatigue hits you emotionally — you're drained from caring so deeply. Burnout wears you out physically and mentally — too many tasks, not enough time or support. Compassion fatigue usually builds slowly from emotional overload, while burnout can come on fast when responsibilities pile up.

Once you can tell which one you're dealing with (or if it's a bit of both), you can take steps to start feeling better. Here's how.

#### If it's compassion fatigue:

- Talk it out. Therapy, peer support groups, or even a close friend who gets it can help you process what you're feeling.
- Take emotional breaks. Even short walks, journaling or five minutes of quiet can help reset your nervous system.
- Practice mindfulness. Grounding techniques and breathing exercises can help reconnect you with yourself when you feel disconnected.

### If it's caregiver burnout:

- Ask for help. Whether it's a family member, professional caregiver or local support service — delegate where you can.
- Take practical breaks. Schedule time off, even if it's just an afternoon. You need recovery time.
- Streamline tasks. Create a caregiving schedule, prioritize what's really essential and don't be afraid to let the non-urgent stuff slide. Dishes and dirty floors be damned — you need a rest!

Most importantly: **you can't pour from an empty cup**. Taking care of yourself isn't a luxury — it's part of what makes you a sustainable caregiver.

You're not alone in feeling this way, and it doesn't mean you're failing.

It just means it's time to give yourself a little of the care you've been giving everyone else.

### Community Partner Highlight

# Text with 9-1-1 (T9-1-1)

If you are a part of deaf, deafened, hard of hearing or speech impaired (DHHSI) community in Canada, you could be able to connect with 9-1-1 call centres through text messages. Learn more at <a href="https://www.textwith911.ca">www.textwith911.ca</a>

Before utilizing this service:

- Register for T9-1-1 with your wireless service provider AND
- Check with your wireless service provider, whether your phone is compatible.



# I named my grief Marlow: learning to gently welcome the uninvited guest

### by JoAnne Connors

Grief has a way of showing up when you least expect it, and for me, it goes by the name of Marlow.

I chose this name because it feels connected to something deeper — something that reminds me of the sea.

"Marlow" comes from an old word meaning "driftwood," and that's how grief often feels to me. It drifts in and out of my life, gently moving with the tide, never quite settled, but always there.

Marlow doesn't ask for permission to arrive. She doesn't announce herself or give any warning. One moment, I might be going about my day, whether it's driving to work or sharing a laugh with friends, and the next moment, Marlow is quietly by my side. At first, this felt unsettling. I thought that if I kept busy enough, maybe Marlow would go away on her own. But grief doesn't disappear when we ignore it. So, over time, I learned that instead of pushing it away, I needed to find a way to live alongside Marlow.

**In the beginning, I tried to avoid her.** I didn't want to feel grief when I was at work or trying to enjoy life. But I soon realized that pushing grief away only made it linger longer.

So, I began to greet Marlow when she appeared. I would say, "I see you, Marlow. I'm here with you, but I can't let you take the lead right now." It became my way of **acknowledging grief without letting it take control** of the moment. I allowed myself to feel, but I didn't let those feelings dictate everything.

This is when I started exploring the whole idea of detachment — not shutting off my emotions, but more letting them come and go, like a piece of driftwood on the waves of the ocean, without holding on to them.

As I pulled from different belief systems, looking for meaning, I found a common theme—that **everything is temporary**—**even how we feel**. Grief, joy, sadness—they all pass eventually. I also got to experience the honour of sitting in sharing circles, where people came together, talked about their feelings and supported each other without judgment. It was where I learned the power of holding space for someone suffering, and what it was like for folks to hold space for me when I was struggling.



When I stopped trying to fight or control what I was feeling, I could just let it come and go, and not let it take over. I wasn't sticking to any one belief system, I was just pulling from different ideas with an open mind, and that helped me deal with grief in a way that made sense to me.

Sometimes, when I'm driving and Marlow sits beside me, I welcome her. I keep my focus on where I'm going, allowing grief to sit quietly beside me without letting it change my course. It's a delicate balance — honouring grief while still moving forward in my life, understanding that **neither my grief, nor my happiness are permanent**. Both are visitors, and I'm learning to welcome them without holding on too tightly.

Naming Marlow has helped me understand that **grief isn't something I need to fight**. It's not about pretending grief isn't there or wishing it away — it's about accepting that it's a temporary visitor.

Marlow is my friendly reminder, a tap on the shoulder, that she is there with me for a moment. Like the waves on the shore or the gentle drift of wood across the water, grief comes and goes. It's a part of my story, but it doesn't have to take over.

Now, when Marlow appears, I invite her to sit quietly with me. I allow her to be present, but I don't let her dominate my life. I've learned that grief is only temporary, and one day, Marlow will leave — quietly, unexpectedly, but not forever. When that happens, I'll be stronger, more at peace and better able to face grief when it visits again. It doesn't need to overwhelm me. Instead, it can become a space for growth, healing and ultimately, peace.

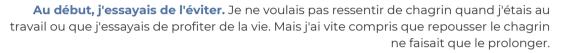


# J'ai appelé mon chagrin Marlow : apprendre à accueillir en douceur l'invité indésirable

### par JoAnne Connors

Le chagrin a le don d'apparaître quand je m'y attends le moins, et pour moi, il s'appelle Marlow. J'ai choisi ce nom parce qu'il me relie à quelque chose de plus profond, quelque chose qui me rappelle la mer. « Marlow » vient d'un vieux mot qui veut dire « bois flotté », et c'est souvent comme ça que je ressens le chagrin. Il va et vient dans ma vie, se déplaçant doucement au gré des marées, jamais vraiment stable, mais toujours présent.

Marlow ne demande pas la permission d'arriver. Elle ne s'annonce pas et ne donne aucun signe avant-coureur. Un instant, je vaque à mes occupations, que ce soit en conduisant pour aller au boulot ou en rigolant avec des copains, et l'instant d'après, Marlow est tranquillement à côté de moi. Au début, ça me dérangeait. Je pensais que si je restais suffisamment occupée, Marlow finirait par partir d'elle-même. Mais le chagrin ne disparaît pas quand on l'ignore. Avec le temps, j'ai donc appris qu'au lieu de le repousser, je devais trouver un moyen de vivre avec Marlow.



J'ai donc commencé à accueillir Marlow quand elle apparaissait. Je lui disais : « Je te vois, Marlow. Je suis là avec toi, mais je ne peux pas te laisser prendre le dessus pour l'instant. » C'est devenu ma façon de reconnaître le chagrin sans le laisser prendre le contrôle du moment. Je me suis permise de ressentir, mais je n'ai pas laissé ces sentiments dicter ma vie.

C'est à ce moment-là que j'ai commencé à explorer l'idée du détachement : ne pas refouler mes émotions, mais plutôt les laisser aller et venir, comme un morceau de bois flottant sur les vagues de l'océan, sans m'y accrocher.

En puisant dans différents systèmes de croyances, à la recherche d'un sens, j'ai réalisé qu'il y avait un thème commun : **tout est temporaire, même nos sentiments**. Le chagrin, la joie, la tristesse... tout finit par passer. J'ai aussi eu l'honneur de participer à des cercles de partage, où les gens se réunissaient pour parler de leurs sentiments et se soutenir sans jugement.

C'est là que j'ai découvert le pouvoir d'offrir un espace à quelqu'un qui souffre, et ce que ça faisait d'avoir cet espace pour moi quand j'étais en difficulté. Quand j'ai arrêté d'essayer de lutter contre mes sentiments ou de les contrôler, j'ai pu les laisser venir et partir, sans les laisser prendre le dessus. Je ne m'accrochais à aucun système de croyances, je puisais simplement dans différentes idées avec un esprit ouvert, et ça m'a aidée à gérer mon deuil d'une manière qui avait du sens pour moi.

Parfois, quand je conduis et que Marlow est assise à côté de moi, je l'accueille. Je reste concentrée sur la route, laissant le chagrin s'installer tranquillement à côté de moi sans le laisser changer ma trajectoire. C'est un équilibre délicat : honorer mon chagrin tout en continuant à avancer dans ma vie, en comprenant que **ni mon chagrin ni mon bonheur ne sont** permanents. Les deux sont des visiteurs, et j'apprends à les accueillir sans m'y accrocher trop fort.

Donner un nom à Marlow m'a aidée à comprendre que **le chagrin n'est pas quelque chose contre quoi je dois me battre**. Il ne s'agit pas de faire semblant que le chagrin n'existe pas ou de souhaiter qu'il disparaisse, mais d'accepter qu'il s'agit d'un visiteur temporaire. Marlow est un rappel amical, une petite tape sur l'épaule, qui me dit qu'elle est là avec moi pour un moment. Comme les vagues sur le rivage ou le doux glissement du bois sur l'eau, le chagrin va et vient. Il fait partie de mon histoire, mais il ne doit pas prendre le dessus.

Maintenant, quand Marlow apparaît, je l'invite à s'asseoir tranquillement avec moi. Je lui permets d'être présente, mais je ne la laisse pas dominer ma vie. J'ai appris que le chagrin n'est que temporaire et qu'un jour, Marlow partira, tranquillement, de manière inattendue, mais pas pour toujours. Quand ça arrivera, je serai plus forte, plus sereine et mieux à même d'affronter le chagrin lorsqu'il reviendra me rendre visite. Il n'a pas besoin de me submerger. Au contraire, il peut devenir un espace de croissance, de guérison et, finalement, de paix.





by Kim Henry

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Death is a universal experience, although everyone interprets and processes it differently. There has always been a level of comfort with death in my family. From a young age, I was present for the dying process of loved ones, attended wakes — some in family homes — and participated in various funeral rites of those who surrounded me. While this might be the norm for my family, not everyone's exposure to death and dying is the same.

One's cultural beliefs, experiences and practices affect their perception and level of comfort with the death and dying. Many of us carry on with life hoping never having to address the influence and meaning of the life cycle until confronted with death head-on. In Western culture in particular, we tend to avoid or fear death. Yet death is inevitable for all of us.



One way people are beginning to engage more openly with this topic is through Death Cafes. Death Cafes provide an opportunity for the curious ones to confront the subject and to become "comfortable with the uncomfortable." I'll admit, I was quite excited when I received an invitation by Norse Ridge Services to co-host a Death Cafe with them and their colleagues this past April. Some years ago, I saw a news feature about a death cafe held in Halifax, and this recent invitation allowed me to explore the concept even further.

The concept of Death Cafes originated with a Swiss sociologist, Bernard Crettaz. His mission, as he saw it, was to "liberate death" from what he called "tyrannical secrecy." Inspired by his work, Jon Underwood and Sue Barsky developed The Death Cafe model as a social franchise. Since the launch of the first Death Cafe, they have been held in many places — including here, in Nova Scotia.

A Death Cafe isn't a fixed physical space, but a gathering, usually with food and refreshments, where people can talk about death. No two cafes are ever the same. Kathryn Murphy from Norse Ridge Services shared that the Death Cafes she hosts offer a space, without an agenda, to discuss the hard subjects, on your terms. The conversation can quickly develop into what you might be looking for in that moment. Patience and kindness are important for the community to find their pace in discussion; however, she notes, one must first be brave. Brave enough to step into the room. Brave enough to listen to others. Brave enough to share.

Being invited to co-host a Death Cafe with Kathryn gave me the opportunity to be brave, too! It took me a long time to step into a cafe. But when I did, what I found was a varied community, a group of both professional and lay persons, sharing their thoughts, stories, experiences, questions and fears around death and dying. While the topic of death can be somewhat unsettling, the room was surprisingly hopeful. It was full of emotion and even laughter.

Once the conversation begun, any discomfort in the room seemed to dissipate. The discussion was moderated for safety, everyone was respectful. For some, it was their first experience with a café, others returned to continue the conversation.

While Death Cafes don't eliminate our fears about death, the healthy conversations help us tolerate them and encourage learning more in a safe environment. Our lack of exposure and preparedness for death leaves us ill-equipped at times for this unavoidable event. By pushing through this discomfort, we can achieve personal growth and development and diminish taboos associated with death.

If you ever have the chance to attend a Death Café, be brave! Step into the room. You might be surprised by what you find there.

"The biggest regret of your life won't be what you did, it'll be what you didn't" (Lee Brice)





# Welcome!

### **Tomi Adesina | Project Coordinator**

I'm happy to join the Social Prescription project at Caregivers Nova Scotia.

With background in Public policy, Communications, Research and EDIA, I'm excited to build strong relationships with healthcare professionals and increase support for caregivers across the province.

As both a caregiver and a care recipient, I appreciate the mission of this organization and am excited to lead this project!

# Welcome back!

**Nicole Byers | Caregiver Support Coordinator** 

I'm very happy to be rejoining the Caregivers NS team after my parental leave. My background is in social work and psychology and I bring valuable skills and life lessons from my early work in child protective services.

I have been a caregiver to my partner during their recovery from surgery, my father and my child, who has complex medical needs. These experiences have given me firsthand insight into the joys and challenges of caregiving.

With my experience as a social worker and a caregiver, I hope to provide support, information and advocacy to the caregivers on the South Shore. I look forward to meeting you.



# **Our team**

### Office

- Jenny Theriault
- Kim Henry
- Ana Merkureva
- Emily Gallant
- Tomi Adesina

### Coordinators

- JoAnne Connors
- Therese Henman-Phillips
- Sheila Landry
- Nicole Byers
- Lyn Stuart
- Leanne Taylor
- Jennine Wilson

## **Our board**

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- Wendy Menczel Vice-Chair
- Brittany Keough Treasurer
- Lindsay Jones Secretary

### Members at large

- Paula Blackmore
- Mary Elizabeth MacLellan
- Sherri Mitchell
- Steven Neatt
- Maggie Roach-Ganaway



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