

# The Beacon

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## Hello caregivers, community partners and friends

May is such a beautiful time of year in Nova Scotia – longer days, more sunshine and that promise of lovely things to come. It’s also a really important time for us, as May is Caregiver Awareness Month.

This month gives us the chance to pause and recognize the **1 in 3 Nova Scotians** who are family and friend caregivers. These are people who show up every day, often quietly and without recognition, providing care, support and love in ways that truly keep our communities together.

Caregiving looks different for everyone, but at its core, it’s about showing up for someone who needs you, with compassion, patience and care.

Throughout the month, we’ll be sharing stories, resources and ways to recognize and support caregivers across the province. And if you are a caregiver, please know that we see you and we are so grateful for all that you do.

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 Benefit: its importance, evolution & future

by Therese Henman-Phillips



Earlier this year, the proposed provincial budget briefly put the Caregiver Benefit at risk.

While the suggested 20% cut to the benefit was reversed following strong public response, those few weeks of uncertainty highlighted two things: how quickly people can come together in support, and how many caregivers did not know this benefit existed.

A benefit that is both essential and under-recognized is a benefit that is fragile in practice, even when it appears stable on paper.

## About the benefit

Introduced in 2009, the **Caregiver Benefit** provides **\$400/month** to eligible caregivers supporting an adult with a high level of disability or impairment, providing 20+ hours of care per week.

The Continuing Care Program assesses eligibility of both the caregiver and care recipient and administers the benefit.

ANNUAL INCOME	FAMILY SIZE and INCOME CATEGORY		
	1	2	3 or more
\$0 to \$31,661	A	A	A
\$31,662, to \$46,662	B	A	A
\$46,663 to \$56,663	C	B	A

**Table:** to qualify, care recipient's net annual household income should be within category A

While the amount often does not cover the full cost of caregiving, it makes a real difference. Caregivers decide how to best use the funds, depending on their situation – it can go towards medications, transportation, respite and more. It's a direct, ongoing support that does not interrupt care and recognizes the essential role caregivers play in our healthcare system.

## The awareness gap

The challenge is that **many caregivers never receive it**. I still frequently meet caregivers who are unaware of its existence.

As of April 2025, 3,303 caregivers in Nova Scotia were receiving the Caregiver Benefit. A meaningful number, but still only a fraction of those providing care. If one in three Nova Scotians are caregivers (roughly 333,000 people), then **only 1%** are accessing this support.

Our goal as an organization is to change that, by making sure more caregivers know about this program and apply.

If you think you may qualify, contact **Continuing care** at **1-800-225-7225**

## First in Canada

Nova Scotia was the first province in Canada to introduce the benefit in 2009. Since then, other Atlantic Provinces launched similar initiatives.

- **Newfoundland and Labrador** matched the amount of our benefit, but targeted caregivers supporting seniors (65+) with low income and high care needs (MAPLe score 5).
- **PEI** introduced a tiered benefit ranging from \$250 to \$1,500, depending on the care recipient's income.
- **New Brunswick** is currently developing a program that would provide \$250 a month to caregivers of aging parents.

## Momentum building

Momentum is also growing nationally.

In 2024, the federal government committed to developing a National Caregiving Strategy, released the following year by the Canadian Centre for Caregiving Excellence (CCCE). Among the recommendations were a national caregiver allowance and improved tax measures to reflect the financial realities of unpaid care.

## The future of the benefit

The progress made to date is significant, but far from finished. Continued advocacy remains essential as we work to protect, strengthen and expand the Caregiver Benefit. Recent proposals, such as the **Caregiver Benefits Act** introduced by the Nova Scotia NDP, signal the growing recognition that caregivers deserve sustained support.

The Caregiver Benefit remains one of the few direct financial supports available to unpaid caregivers in Nova Scotia. Our work is to make sure every eligible caregiver knows about it, and that the program evolves with the realities caregivers face, from rising costs of living to aging population.

Caregivers are carrying our healthcare system. The least we can do is make sure the system supports them, too.

# Role reversal in caregiving

by Kim Henry

As parents age, many families experience a shift. It might start with helping drive your parent to an appointment as they become less mobile, or picking up some medications. Gradually, with declining physical health or cognitive changes, small errands turn into managing daily care, medications and finances. This is role reversal – a shift many families experience, but few feel prepared for.

## What is role reversal

At its core, role reversal means children gradually taking on the caregiving responsibilities once handled by their parents. While common, it can reshape family roles in ways that feel unfamiliar and, at times, overwhelming.

Caregiving typically falls into **three categories**: managing daily logistics (cooking, cleaning, finances – also known as IADLs), providing personal care (bathing, dressing – and other ADLs) and emotional care. The last category is often complex, spanning from offering support, reassurance and companionship to becoming a full confidant for your parent.

## Emotional struggles

For **young caregivers**, role reversal can be particularly challenging. They often experience parentification – taking on tasks and responsibilities that exceed their age and fall outside traditional parent/child roles. The pressure of being responsible for a parent's wellbeing can lead to heightened anxiety, confusion about identity beyond caregiving and missing out on important milestones.

Even for **adult children**, the emotional weight of caregiving can be significant. Many balance work, friendships, family life and personal responsibilities with their caregiving role. It's common to feel pulled in all directions, wondering whether you're doing enough. Guilt, resentment and exhaustion can slowly grow, especially as free time begins to shrink.

At the same time, **aging parents** often struggle with the loss of independence. They may deny the level of support they need, resist or selectively accept care, question caregiving decisions, feel embarrassed or fear becoming a burden.



In many cases, both parent and caregiver are grieving – one mourning a loss of autonomy, the other – loss of time and the emotional weight of stepping into such a heavy, intimate role. If not acknowledged, this shared grief can place strain on the relationship and lead to conflict.

## What can help

One helpful approach is **viewing the role reversal as a partnership**, not “parenting a parent.” Including parents in decisions about their care whenever possible can preserve their sense of dignity and control over their life. Open communication about care-related decisions and sensitive topics is best done early, before a crisis arises. These discussions aren't always easy, but they can help achieve full understanding, avoid conflict and build mutual respect.

**Establishing healthy boundaries** is equally important. Caregiving doesn't mean doing everything alone. Delegating tasks, seeking support from family or external sources and being honest about your limits is essential for preventing burnout. Protecting your wellbeing is not selfish – it's essential.

Look out for a few **signs that the care relationship is becoming strained**. For caregivers, this might look like irritability, chronic stress or neglect of their own health. For aging parents, secrecy about medications or their health is often a sign they are uncomfortable with the care arrangement.

Ultimately, role reversal in caregiving is less about replacing the parent role and more about reframing the relationship. When approached with empathy, clear boundaries, mutual respect and open communication, the transition can lead to a strengthened family bond, one where both parties maintain a sense of dignity and connection.

# After the “Goodbye”: handling your care recipient’s digital life

by Ben Robertson

You took care of everything: the will, the power of attorney, the personal care directive. Even the funeral preparations. Just as you begin to catch your breath, a Facebook notification appears. “Share a memory”, with the person you just lost. For many caregivers, this automatic message can be quite traumatizing.

After a person passes, social media becomes an emotional minefield. “Happy Birthday” messages from people who didn’t know, nudges to invite them to a new event, “You might know them” suggestions. Social media accounts do not disappear on their own, they sit indefinitely, sometimes becoming beautiful spaces of remembrance, sometimes – unexpected sources of grief.

As caregivers, we know how to meet physical, emotional and spiritual needs. But one responsibility rarely features in a typical advanced care plan: what happens to a person’s digital life after they pass?

## What each platform allows

- **Facebook** and **Instagram** offer two options: to [memorialise](#) the profile or permanently delete it. Memorialised profiles do not appear in public spaces or notifications – they become a space for friends and family to share memories. Encourage your care recipient to assign a [Legacy Contact](#) – a person who manages the page after memorialisation.
- **Google** and **YouTube** let users decide in advance what happens to their data. In [Inactive Account Manager](#), users can choose several people to “inherit” parts of their account – videos, photos or emails.
- **TikTok** and **X (formerly Twitter)** allow families to remove an account by submitting the death certificate. Before you submit the request, archive and download the profile, as you will lose all content permanently.
- **LinkedIn** only allows permanent account removal. There is no archiving option, so save the career history and any meaningful content manually beforehand.

## One conversation can change everything

The difference between a painful experience and a peaceful one often comes down to a single conversation. You, as a trusted caregiver, are perfectly positioned to start it. It doesn’t have to be heavy.

During a calm moment simply ask:

**“Have you ever thought about what should be done with your digital accounts, like Facebook or email, after you’re gone?”**

Many care recipients, when asked directly, have very clear wishes. They simply need someone to ask.

## Here are four simple steps you can take today:

- Encourage the care recipient to assign a **Facebook Legacy Contact**
- Suggest setting up Google’s **Inactive Account Manager**
- Help **document account wishes** in the Advance Care Plan
- Ensure **login information** is known and stored securely

Planning a digital afterlife isn’t about dwelling on death.

This is one of the most considerate final gifts you can help someone give to their loved ones.



# Après les « adieux » : gérer la vie numérique de la personne dont vous vous occupez

par Ben Robertson

Vous vous êtes occupé de tout : le testament, la procuration, les directives anticipées. Même les préparatifs funéraires. Et quand vous commencez à reprendre votre souffle, une notification Facebook apparaît. « Partagez un souvenir » avec la personne que vous venez de perdre. Pour de nombreux aidants, ce message automatique peut être très traumatisant.

Après le décès d'une personne, les réseaux sociaux deviennent un champ de mines émotionnel. Des messages « Joyeux anniversaire » envoyés par des inconnus, des notifications pour l'inviter à un nouvel événement, des suggestions du type « Vous connaissez peut-être cette personne ». Les comptes sur les réseaux sociaux ne disparaissent pas d'eux-mêmes, ils restent actifs indéfiniment, devenant parfois de beaux espaces de mémoire, parfois – des sources inattendues de chagrin.

En tant qu'aidant(e)s, nous savons répondre aux besoins physiques, émotionnels et spirituels. Mais une responsabilité figure rarement dans un plan de soins anticipés classique : qu'advient-il de la vie numérique d'une personne après son décès ?



## Ce que chaque plateforme permet

- **Facebook** et **Instagram** proposent deux options : **commémorer** le profil ou le supprimer. Les profils commémorés n'apparaissent pas dans les espaces publics ni dans les notifications – ils deviennent un espace où les amis et la famille peuvent partager des souvenirs. Encouragez la personne dont vous vous occupez à désigner un **contact légataire** – une personne qui gèrera la page après la mise en mémoire.
- **Google** et **YouTube** permettent aux utilisateurs de décider à l'avance du sort de leurs données. Dans le **Gestionnaire de compte inactif**, les utilisateurs peuvent choisir plusieurs personnes pour « hériter » de certaines parties de leur compte – vidéos, photos ou e-mails.
- **TikTok** et **X (anciennement Twitter)** permettent aux familles de supprimer un compte en fournissant le certificat de décès. Avant de soumettre la demande, archivez et téléchargez le profil, car vous perdrez tout le contenu de manière définitive.
- **LinkedIn** autorise uniquement la suppression définitive du compte. Il n'y a pas d'option d'archivage, alors enregistrez manuellement au préalable l'historique professionnel et tout contenu significatif.

## Une seule conversation peut tout changer

La différence entre une expérience douloureuse et une expérience sereine se résume souvent à une seule conversation. En tant qu'aidant de confiance, vous êtes parfaitement placé pour l'engager. Cela n'a pas besoin d'être un sujet lourd.

Dans un moment de calme, demandez simplement :  
**“As-tu déjà réfléchi à ce qu'il faudrait faire de tes comptes numériques, comme Facebook ou ta messagerie, après ton départ ?”**

De nombreuses personnes dont on s'occupe, lorsqu'on leur pose directement la question, ont des souhaits très clairs. Elles ont simplement besoin que quelqu'un leur pose la question.

## Voici quatre mesures simples que vous pouvez prendre dès aujourd'hui :

- Encouragez la personne dont vous vous occupez à désigner un **contact légataire** Facebook
  - Suggérez-lui de configurer le **Gestionnaire de compte inactif** de Google
  - **Aidez à documenter les souhaits du titulaire** du compte dans le plan de soins anticipés
- Assurez-vous que **les informations de connexion** sont connues et conservées en toute sécurité

Planifier sa vie numérique après la mort ne revient pas à ruminer la mort. C'est l'un des derniers cadeaux les plus attentionnés que vous puissiez aider quelqu'un à offrir à ses proches.



# Major surgery caregiving: a personal story

by JoAnne Connors

We got the call from the surgeon's office: "Your hip replacement surgery will be in three weeks."

After waiting more than a year, the date felt like a starting line, not just for the surgery, but for my role as a caregiver.

## Preparations

Those three weeks before surgery became a time of focused preparation. As a caregiver, I was not only helping get things ready, I was trying to think a few steps ahead. We **set up the house, filled prescriptions** in advance and **gathered the equipment** we'd need. There were a few hiccups along the way, but having things in place gave me a sense of steadiness. It meant that when we came home, I could focus on supporting recovery instead of scrambling to manage logistics.

Preparing mentally was just as important. We attended the hospital's **education class** together, which made a real difference. Hearing the same information, like what movements were safe, what to avoid and what recovery might look like, meant I didn't have to guess or second-guess once we were home. It helped me feel more confident in my role and allowed us to approach recovery as a team.

I also went to the **pre-surgery appointment**, where everything was reinforced. At the time, it felt like a lot to take in, but once we were home, that knowledge became essential. I knew what to watch for, what was normal and when to reach out for help. Supporting the preoperative exercises also became part of my role, encouraging consistency, helping build routine and creating a sense that we were both actively preparing.

## Post-surgery care

After surgery, caregiving became immediate and intense. There was no hospital stay, and we went straight home, which meant stepping into the role right away.

**The first few days were the hardest.** Managing medications, making sure doses and timing were correct and staying alert to changes created a constant undercurrent of responsibility. Even simple tasks, like standing up, getting into bed, washing and using the bathroom, required planning, patience and presence. Nothing could be rushed.

Progress came in small, steady steps, and as a caregiver, I learned to **notice and support those moments**: a short walk down the hall, sitting up a little longer, a bit more confidence each day doing the post-operative exercises. These were physical milestones, signs that things were moving forward.

Sleep was difficult, especially in the beginning. Nights were long, and discomfort affected both of us. I focused on creating as much comfort as possible, from adjusting pillows, keeping to a medication schedule and trying to anticipate needs, but rest took time to come.

That shared fatigue is something caregivers often carry quietly.

Pain management quickly became part of the daily routine. Keeping track of medications, watching the clock and checking in regularly required constant attention. When questions came up, especially about side effects, calling 811 to speak with a nurse was an important support. It reassured me that I didn't have to figure everything out alone.

## Looking back

I didn't expect **how much of caregiving would be emotional**. Even over those weeks, there was a constant balancing act between helping and stepping back, supporting and preserving independence. The instinct was to do everything, especially when time felt short. But I had to learn, quickly, that part of good caregiving is **knowing when not to step in**, despite my tendency to take over.

Listening became one of the most important things I could offer. **Not assuming what was needed**, but asking and really listening to the answer. Some days required more hands-on help, others – required space. Because we shared the same information ahead of time, those conversations were easier. We weren't guessing, we were singing from the same songbook.

That's where my perspective shifted. I began to see clearly that **short-term caregiving is still caregiving**. The time frame doesn't make it easier; it just concentrates everything. The responsibility, attention and emotional presence are all necessary, just compressed into a shorter, more intense period.

In the end, those weeks were about more than recovery from surgery. They were about showing up consistently, adapting in real time and learning how much caregiving asks of you, even in the short term. My self-care was very important as well.

Short-term caregiving may feel like a sprint, but it still requires the care, awareness and endurance of a much longer caregiving journey.

# JoAnne Connors retires

by Ana Merkureva

If JoAnne St.Amour-Connors were a character, she'd be Mary Poppins: a highly skilled, almost magical woman who arrives in a new place, changes things for the better – and moves on when the time is right.

When JoAnne was 19, she moved North in search of work. She arrived in a small town of Hay River with little money, no job and no place to stay. Relying on kindness of strangers for shelter, she worked early shifts at a local bakery before securing a position in one of the shipyards. Over the next three years, she saved enough to become the first in her family to attend university. After graduation, she returned to give back to the community.

## Community firsts

She created a few local "firsts": the first culturally-aware preschool with Katlodeeche First Nations and the first francophone school. Both came with their own challenges.

**The preschool** was a race against time. "They received full funding, but had to spend it by the end of fiscal year." JoAnne stepped in and turned a handful of rooms into a working preschool: recruiting staff, securing licensing, arranging a van so children who lived far could attend. For some families, it became the first Indigenous preschool within reach. She ensured no child was left behind, adjusting the curriculum to include kids with special needs, with elders as advisors.

**The school** was a fight for a community. "I met parents interested in French Immersion. The English school board said if we get enough people to sign up, we can make it."

Though they secured signatures, the board withdrew support. The community split: some backed a French school, while others feared it would drain resources from the English system. Three years of meetings and paperwork followed in the fight for funding and approval.

"I learnt how the personal is political, because politics were bleeding into my home. I was personally attacked at school board meetings, in public, even at the grocery store." Despite the pushback, the school eventually opened, and her daughter Renée was among the first nine students.



**Photo:** some of the first students of École Boréale, 1998



**Photo:** classroom in Rawlins, Wyoming, 2016

## Filling the gaps

JoAnne valued accessible and engaging education, especially in rural areas. When her husband Rick got an opportunity to work in rural US, JoAnne followed – and soon became essential to local libraries and schools.

Within months she went from stocking shelves as a volunteer to **running children's programming** across eight libraries in the county. She filled empty corners with craft bins, brought books by Indigenous authors and designed hands-on programs that made kids curious about their state's history, culture and nature.

She also became a **coveted substitute teacher**. "Substitute teachers in Wyoming were rare. Often they were kids coming out of high school." In class, she challenged students to see history from multiple angles – asking who was missing from the narrative and why, and using humour to make classes memorable.

## Supporting families

For over two decades, JoAnne supported those who care for others.

At the **Family Resource Centre**, she helped parents in rural Cape Breton feel more confident – and less isolated – through programs on everything from child development to positive parenting. One special initiative, Maggie's Magic Cupboard, was "all about nutrition, shopping on budget, reading labels and understanding them better" – skills especially important in a community where many families face food insecurity.

At **Caregivers Nova Scotia**, she introduced two educational workshops: "Caregiver Stress Management" and "Understanding Dementia Behaviours", helping caregivers support both their loved ones and themselves. She helped the organization expand to Cape Breton, organizing the first support groups on the island, and later ran support groups in Halifax.

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“Support groups and workshops were important, but mostly, I loved giving caregivers a place where they feel supported, heard and seen.”

JoAnne was a true ally and a fierce advocate for all caregivers. And a fantastic colleague.

“JoAnne has been more than my mentor, she's been my steady anchor. JoAnne's legacy for me is her unwavering support, care and love that I received so freely,” shared Ben Robertson, Outreach and Caregiver Support Coordinator.



**Photo:** JoAnne St. Amour-Connors at her last support group, Spryfield, 2026

## Wind changes

“I'm leaving work that I absolutely love. But I feel comfortable knowing it's in good hands.”

Whenever JoAnne leaves, she always leaves something behind to remember her by. A school that became a true francophone hub in the North. A preschool filled with laughter. Books on the shelves. Workshops that make people confident in themselves. And communities of caregivers, who met in her support groups.

Thank you, JoAnne. And happy retirement!

## Social Prescribing Project

If you're a **medical professional** working with caregivers, you can now refer them to our organization directly through EMRs!

### We're integrated into:

- ✓ Accuro
- ✓ Med Access
- ✓ Ocean MD

Find **step-by-step** guides in our “How to refer” section:

[Learn more](#)



*Caregiver Appreciation tea*

May 21 | 1-3 p.m. | Kiwanis Grahams Grove

Join us for a cozy caregiver celebration.  
Delicious tea in vintage cups, sweet treats, flowers and lots of cheer!

RSVP: [Info@CaregiversNS.org](mailto:Info@CaregiversNS.org)  
seating is limited



# Annual general meeting

June 8, 2026 | 4:30 p.m.

Canada Games Centre, Halifax

RSVP: [Info@CaregiversNS.org](mailto:Info@CaregiversNS.org)

## Our team

### Office

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

### Coordinators

- Nicole Byers
- JoAnne Connors
- Therese Henman-Phillips
- Ben Robertson
- Lyn Stuart
- Leanne Taylor
- Jennine Wilson

## Our board

### Executive Officers

- Steven Neatt - Chair
- Wendy Menczel - Vice-Chair
- Brittany Keough - Treasurer
- Ruvu Norah Mugara - Secretary

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- Robin Carter
- Sarah Cluett
- Jenna Fralick
- Mary Elizabeth MacLellan
- Mary Protos
- Emily Tabor
- Catherine Young