



## What's New?



### "Hidden Population"

Former social work students shed light on the often unrecognized contribution informal caregivers provide to the healthcare system.

### Challenges and Triumphs

Informal caregiver speaks to her caregiving experiences and how the NB caregiver can be better supported.



### Innovation and Care

Informal Caregiver and CareLink service user shares how technology allowed her parents to "age in place".

## Informal Caregivers of New Brunswick

The past few months have been very busy for the Collaborative. In addition to hosting three St. Thomas social work students for their social action placement last fall, we also said goodbye to former Coordinator Beth Arsenault. More recently, we have welcomed a new coordinator to take over the reins!

Given the liveliness of the past few months and the unique experience of hosting three social work students, this issue of **Neighbours in Aging** will bring readers up to date on the work that students completed in their exploration of informal caregivers across the province.

In addition to highlighting the compelling findings from their research study, we hear the first-hand account of a New Brunswick caregiver who strives to use her own experiences to advocate for this population.

Finally, we will explore how technological innovation is being utilized as an alternative to the traditional approach to caregiving.

Happy Reading!

hi, my name is...

*Erin!*

Hello readers,

As the new editor of Neighbours in Aging, I'd like to introduce myself.

I am a graduate from St. Thomas University with degrees in Gerontology and Social Work and have a passion for all things AGING. I'm overjoyed to be in a position that engages aging discourse across the province and will work my hardest to keep communities connected through highlighting your stories and initiatives!

Help me get to know you by sharing what's happening in your community or organization. Let's keep the conversation going!

Email your stories, ideas and updates to [admin@nbcollab.ca](mailto:admin@nbcollab.ca)

Looking forward to hearing from you!

Erin  
Coordinator



## “Hidden Allies” to the Healthcare System

### *Uncovering the realities of Informal Caregiving in NB*

Last fall the Collaborative had the privilege to host three St. Thomas social work students as they completed their social action placement. Morgan Downs, Carly Furlong, and Erin Jackson launched a province-wide survey to explore and uncover the hidden socioeconomic costs of informal caregiving in order to understand how caregivers can be better supported.

On their quest for discovery, students worked diligently to reach as many informal caregivers as possible, networking with community organizations and publicizing on social media in order to spread the word on their research.

In a short, two-month period, the survey managed to reach 92 informal caregivers across 13 counties in the province. While only half of respondents fully completed the survey, students quickly learned that informal caregivers in the province know what is working for them as well as where increased supports are needed.



### *What do Informal Caregivers do?*

Upon compiling survey results, students were quick to define informal caregivers as the “**hidden allies**” to NB healthcare system as they often take on multiple roles and responsibilities.

Results found that caregivers most often provide assistance in the areas of transportation, shopping, financial support, meal preparation, home maintenance, medication administration, and activities of daily living.

Results also indicated that 96% of respondents provide emotional support and reassurance to those they are caring for. Given these results, one cannot deny the important contribution caregivers provide, not only to the care receiver, but the larger healthcare system.

### *What are the costs of Informal Caregiving?*

One of the main objectives of the student’s research was to explore the ways in which caregiving responsibilities interact with the other areas of the caregiver’s life.



**Students uncovered that caregiving responsibilities interact with the physical, financial, emotional, and social areas of a caregiver’s life.** Photo Credit: Informal Caregiver Infographic

Respondents noted that they experience difficulty in meeting their own personal needs, such as time for self-care, sleep and exercise. In addition to personal needs, balancing financial, work, and personal relationship responsibilities were also highlighted.

### *Are Informal Caregivers being supported?*

32% of informal caregivers reported that they do not take time for relief when feeling overwhelmed...**Why?**

- They do not have anyone available to help
- They feel uncomfortable asking for assistance
- They feel as though they need to take on the full responsibility

If they do receive assistance...**who** do they turn to?

- Family and friends
- Home health aids
- LTC respite beds & day programs

## What's needed to better support Informal Caregivers?

Based on the research findings and suggestions made by the respondents themselves, students identified four areas in which increased supports and services could be set in place to better support informal caregivers across the province.

### Education, Training, and Resources...

Respondents expressed their interest in attending educational and training workshops on adult care and self-care practices in order to increase confidence and capacity as an informal caregiver. The desire for reliable, unbiased, and accessible internet resources was also expressed.

### Increased Relief, Respite, and Support Services...

A high number of respondents expressed the need for more relief and respite services to turn to in order to avoid caregiver burnout. Respondents also expressed their interest in attending caregiver support groups to share and learn from fellow caregivers.

### Increased Services in Rural Areas of NB...

Respondents addressed the inconsistency in access to services across the province. A number of respondents expressed the need for equal access to services such as transportation, delivered meals, accessible medical care, and day programs in rural areas of the province.

### Help Navigating Systems and Services...

Informal caregivers need assistance navigating the multiple, separated systems they may use. Respondents expressed the need for assistance in the areas of locating care services, determining LTC options, and access to support following the death of the care receiver.

*I felt privileged to be able to help.*

*~Informal Caregiver*



## Why is this important to talk about?

While the main objective of this research was to uncover how informal caregivers can be better supported, students were also interested in exploring the meaning making that comes from caring for the people we love. Students provided the opportunity for respondents to express how their informal caregiving experiences have impacted them in a positive, meaningful way. Here are some of the common themes they found among responses.

- Growing closer to the loved one
- Strengthening family relationships
- Personal growth, inner strength, patience
- Making new friends & connections
- Satisfaction in caring for those who have or would care for you

## Final Thoughts...

While the research completed by social work students only captured an introductory snapshot into the lived realities of informal caregivers in New Brunswick, results were telling. This research study served as a platform to give this "hidden" population a voice to not only express the ways in which they need to be better supported, but also bring attention to the important contribution they provide in sustaining our present healthcare system!

For more information on this research study please contact Erin Jackson at [admin@nbcollab.ca](mailto:admin@nbcollab.ca).

## Juggling Multiple Roles

### *Interview with an Informal Caregiver*

Recently I interviewed informal caregiver, Nancy Adams, to hear a first-hand account of the challenges and triumphs of taking on this role. This caregiver story situates itself along a four year caregiving journey that highlights the power of family support and teamwork.

Adams found herself cast into the position of service navigator, advocate and caregiver after her mother experienced her first stroke, four years ago. At the time of her stroke, Adams' mother was living with her husband who is ten years older than her. Soon after, her mother was approved for a few hours of homecare a week. While homecare services looked after most household chores, Adams did the grocery shopping and her father learned to take care of bills – it was a joint effort!

Care requirements changed as her mother continued to experience additional strokes over the next couple of years. As homecare hours increased, so too did her role as advocate and supervisor of scheduling. More recently, Adams' mother experienced a stroke that left her unable to continue living in her home. She now lives in a nursing home outside of her community while her husband remains in their home.

I asked Adams to identify some of the challenges she and her family have experienced throughout the caregiving journey. Residing in a rural area of the province, the family at times experienced a shortage of available respite services, to which they compensated for themselves.

Covering all the caregiving bases eventually did have an impact on the family. Adams found herself missing out on work hours and time spent at home with her spouse and children.



She spoke of the impact this role also took on her father. “The most difficult part was seeing the toll caregiving took on my dad who is in his 80’s,” said Adams. Adams hopes to see more programs and services such as adult day programs and meal services become available in rural areas to help fill some of the gaps.

Having a support network to depend on appeared to be how the family adapted to caregiving challenges and expectations. “Having a large, close knit family helps...having them to lean on and talk through issues with was vital during the caregiving journey”, stated Adams.

*Adams' family support system consisted of five siblings, herself and her father...*



I ended our interview by asking Adams to explore what it means to be a caregiver for a loved one. “Knowing that I am able to give back to my parents who were always there whenever I needed them is the most rewarding part”, she first explained.

Adams then went on to eloquently describe that caregiving involves having the ability to juggle multiple roles in hopes that everything will all work out. She expressed that she worries about other informal caregivers who may not have the exceptional support system that she has, which motivates her to continue to advocate for increased supports and services province-wide. Finally, Adams spoke to the lessons she learned about herself. “It has taught me a lot about myself personally, mostly that I am stronger than I thought,” she described.

Adams’ caregiving story, while unique, resonates with much of what many informal caregivers experience throughout their caregiving circumstances. Not only did she speak to hurdles one can face when navigating systems and services, but also the impact this can have on balancing the many roles we fulfill in our lives.

Her story also exemplifies the importance of being supported – emotionally, socially, and physically. While Adams was fortunate enough to have other people in her life to help take on some of the caregiving responsibilities, she too recognizes how essential it is to have dependable community supports and services to rely on, particularly in rural areas of the province.

The Collaborative would like to thank Nancy for sharing her experiences and recommendations with **Neighbours in Aging**.



## Technology and Caregiving

### *An Innovative Approach to Care*

With the rapid advancement of technology in society, it’s not surprising that we have seen an increase in innovations that cater to the - also rapid - changes in population demographics. With CareLink Advantage being a technological approach to care that has been in New Brunswick for a few years now, one may wonder just how helpful it can be for the informal caregiver.

## **Care Link**

*Independent Living Solutions*

### *What is this service?*

For those who may not know, CareLink Advantage is a 24/7 home monitoring system that offers a variety of sensors and monitoring tools that helps to keep older adults with chronic illnesses or disabilities living independently for as long as possible. The service also ensures the caregiver that their loved one is safe while living independently.

### *How does it work?*

The service is comprised of various products, such as motion detectors, contact sensors, and video

monitoring that will send an alert to caregivers in cases of wandering, falls, and medication compliance. Once an alert is sent, the caregiver can then view the real time video to assess the situation and take appropriate action, such as making a phone call, visiting the loved one, calling a neighbor, etc. As sensors and monitors are activated, the information is logged into a dashboard, which allows the caregiver to get a clear picture as to how their loved one’s day is spent safely.





### *Why choose CareLink Advantage?*

I recently spoke with John Whitehead, President of CareLink Advantage to find out how the service supports the informal caregiver. Whitehead was quick to state that it helps the caregiver do their job better. Not only does it reduce the worry around what might happen while they may not be able to be physically present with their loved one, it also allows them to fulfill the wishes of their loved one, which is often to remain in their home as long as possible.

He said that many informal caregivers hit a point where they can no longer risk the worry of what “might” happen, which then leads to burnout and considerations for higher levels of care. With CareLink in place, these concerns can be better assessed with peace of mind.

### *What does the informal caregiver think?*

I was fortunate enough to have also gotten the chance to speak to an informal caregiver who has used CareLink services to help with the care of both of her parents, who lived with a dementia diagnosis.

Cindy Grant began using the service in 2009 when her family felt there were no other options for her parents. She always believed it would be too expensive to use the service but soon realized it was affordable, at only \$90 per month for two cameras, the medication compliance tool, and a bed alarm. Using the service for two years, Grant told me CareLink changed her life and the end of life care for her parents. So, **how** exactly did it help?

### **Long-Distance Caregiving**

CareLink Advantage allowed Grant to fulfill her caregiving responsibilities from a distance. When her parents were first diagnosed, the family moved them from PEI back to NB. This, however, was not where they wanted to be. With CareLink, they were able to move her parents back to PEI for the summers as she would monitor from NB.

If her parents needed any type of assistance, a family member or neighbour close by would step in. In addition to this, Grant mentioned that if she left for vacation, all notifications could be switched over to a family member with the simple click of a button.

### **Aging in Place**

Grant also spoke to how the service allowed her parents the chance to stay where they wished, together on PEI. Grant informed me that because of CareLink, her father never had to enter long-term care. Her mother, now in care, was able to remain independent and with her husband for a longer period of time.

### **Alternative and Individualized Approach**

I spoke briefly with Grant about how some caregivers may be apprehensive to use this type of innovation. Grant reiterated the fact that this is an alternative service that people can use as an option, if it works for them. Grant shared that she used this service in conjunction with others. While they also used homecare, the hours weren't extensive, so they used CareLink in addition. She also mentioned that her father wasn't fond of having people in his home, so CareLink provided a layer of protection without being intrusive.

Grant stated that it is an individualized service that caters to each caregiving situation. The CareLink staff ensures families receive a clear explanation as to how their system works and are available for 24 hour support.

**For more information on CareLink Advantage and their services, please visit their website:**

<https://carelinkadvantage.ca/>