

# The Beacon

Spring/Summer 2018

Volume #10

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

## May is Caregiver Awareness Month

Recently I was asked why Nova Scotians should recognize May in this fashion. Unlike many questions related to caregiving, this one is easy to answer.

One in three Nova Scotians provides some form of care to a family member or friend. Due in part due to our aging population, that percentage is 5% higher than the national average. Seventy-five percent of all the care provided in the home is given by unpaid caregivers. It is estimated that the assistance provided by caregivers saves the Canadian taxpayer \$66 billion annually. Without support from caregivers, many people would be unable to remain in their homes, swamping our healthcare system.

Caregiving is rewarding, but also demanding and stressful. To continue to function effectively, caregivers need information, education, and support. This is what Caregivers Nova Scotia offers.

Family and friend caregivers deserve the recognition and support of all Nova Scotians. Join us in saluting them throughout May.

Regards,  
Angus Campbell, Executive Director



3433 Dutch Village Road, Halifax, NS B3N 2S7  
Tel. 902.421.7390 | Toll-free 1.877.488.7390  
[Info@CaregiversNS.org](mailto:Info@CaregiversNS.org) [www.CaregiversNS.org](http://www.CaregiversNS.org)

## Benefits Update

By Maggie Roach-Ganaway, Cape Breton Region

Change is in the air!

There is good news for family and friend caregivers across Nova Scotia. The Department of Health and Wellness has announced changes to the [Caregiver Benefit](#) and the [Supportive Care](#) programs that will help more unpaid caregivers of Nova Scotia. Both programs are administered through Continuing Care.

The Caregiver Benefit provides eligible caregivers with \$400 per month, acknowledging the assistance they give to a family member or friend. This benefit is welcomed by all eligible caregivers, especially those who may have given up their paid work to care for their loved one. In April, it was announced that an additional 600 households will receive the Caregiver Benefit beginning this year.

The annual income of the care recipient is one of the determining factors of eligibility. If the care recipient is part of a couple, the household income cannot exceed \$37,209 and, if single, the annual income cannot exceed \$22,125. Also, the caregiver must be giving at least 20 hours of care per week to be eligible for this benefit. The Department of Health and Wellness have adjusted the method of assessment to allow those requiring it the most to get first access to this funding. Please note that although this is not taxable income, it is reportable to the Canada Revenue Agency and may have some impact on a caregiver's Guaranteed Income Supplement. Check with your tax preparer before proceeding.

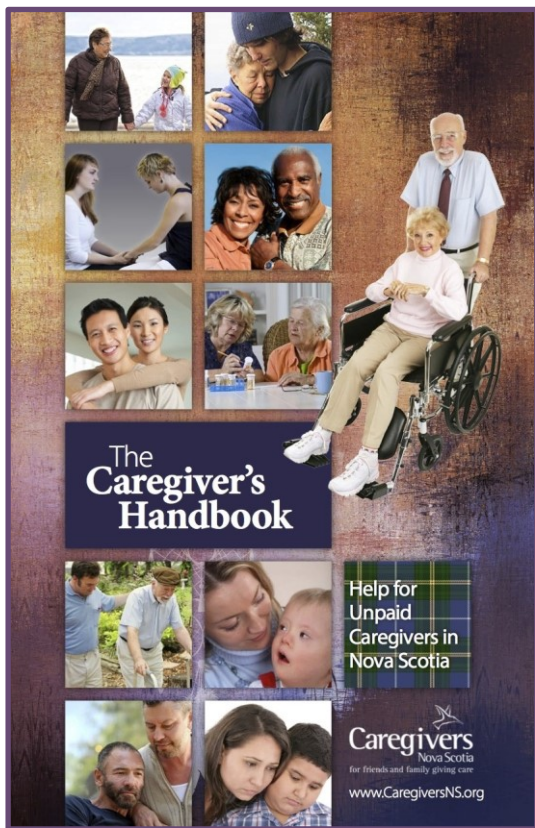
The Supportive Care Program provides funding to support care recipients with cognitive impairments by providing \$500 per month to pay for home support. It is ideal for the care recipient who needs more consistency with care providers as you hire your own staff. The program reimburses costs for services such as meal preparation, personal care, and respite. Recently, this funding has been expanded to include fees for Adult Day Programs (ADPs) if it is part of the prescribed care plan. This is great news for caregivers, as it offers another option for respite as well as stimulating and meaningful programming for the care recipient.

Please contact Continuing Care at 1.800.225.7225 for more information on these valuable programs and to determine whether an additional assessment is required. NOTE: A complete list of [Adult Day Programs](#) across Nova Scotia can be found on our website or by calling us at 1.877.488.7390.



A [fidget lap quilt](#) and [fidget muffler](#) shared by some Support Group members. Great for keeping restless fingers busy and warm.

Thank you  
**Nova Scotia Cancer Care Program**  
 for generously funding a reprint of  
 our Caregiver's Handbook.



Executive Director Angus Campbell writes a monthly caregiving column for the Chronicle Herald Senior Living section.



## Capellini Frittata (serves 4)



This is a nice, light, and nutritious meal that is quick to prepare and VERY tasty.

- ½ cup uncooked pasta in small pieces
- 2 tsp. olive oil
- 1 small red pepper\*, diced
- 1 small red onion\*, diced
- \* (substitute ham, bacon, tomato, asparagus, etc.)
- 6 large egg whites plus 2 whole large eggs
- 1/3 c. Parmesan cheese, grated
- ¼ c. low-fat milk
- ½ tsp. salt
- ¼ tsp. hot pepper sauce (optional)

Cook pasta in 3 c. hot water; drain and set aside.

Caramelize peppers and onions in olive oil in a 10-inch non-stick skillet with a heat-safe handle.

Whisk eggs and egg whites and remaining ingredients. Stir in pasta and pour over vegetables. Cover and cook on the stovetop for 3 minutes until it is set around the edges. Uncover and place in oven at 425° and bake 6 minutes longer or until set in center.

To serve, invert onto a serving plate and cut in wedges. Serve with a small salad and crusty bread.



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](http://www.CaregiversNS.org) and sign up at the bottom of any page.

## #CGAware 2018

By Carlye Stein, Research and Operations Coordinator

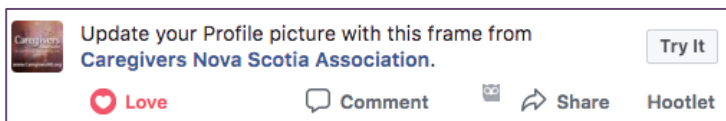
Last year we developed a special area of our website dedicated to caregivers as part of Caregivers Awareness Month. It was such a huge success we've done it again this year. The area is called **#CGAware2018** and you'll find it under the Events tab. We're also excited to bring you two new social media campaigns.

1. **What I Learned from TiAC** - We'd love to hear what you learned from the new [Transitions in Adult Care](#) module of our website. See the back page of this newsletter to find out why we're so excited about TiAC and how it can help you.

Download and print the [TiAC photo page](#). Then, in the space provided, write down the words or concepts from the module that had the most impact on you (we've found that fewer words in large print works best). Hold up the photo page, take a picture of yourself, and post it on social media using the hashtag #CGAware2018. Tag your friends and colleagues and encourage them to share what they learned.

If you're not on social media but want to join this campaign, email your photo to us at [Research@CaregiversNS.org](mailto:Research@CaregiversNS.org). We can post it on our Facebook page, display it with other photos in the **#CGAware2018** area of our website, or both. Please state in the email that you give us permission to share your photo.

2. **#CGAware2018 Facebook Frame**: You'll be able to add a frame to your profile or other picture on Facebook after May 1<sup>st</sup>. Go to Caregivers Nova Scotia's Facebook page (or to the page of someone you know who has used our frame). At the bottom of a photo that has the frame, you'll see this:



Click the **Try It** button and follow the instructions to add our frame to your photo. Once you have added the frame, you can turn it on for a day, a week, or for the entire month of May. Remember to add **#CGAware2018** to relevant posts on social media throughout May to keep the conversation going.

Together with Family Caregivers of British Columbia and Caregivers Alberta, we would like to extend  
**Congratulations**  
and welcome to our new sister organization launched April 3<sup>rd</sup>.

THE ONTARIO  
**Caregiver**  
ORGANIZATION  
[ontariocaregiver.ca](http://ontariocaregiver.ca)

## Transitions in Adult Care (TiAC)

By Cindie Smith, Northern & Eastern Mainland Region

Caregivers often tell us that imagining the journey ahead leaves them feeling unprepared and anxious. Among their frustrations is not knowing who does what and how to reach the appropriate clinician, agency, organization, or department for the services and information they need.

In responding to this widely felt need, Caregivers Nova Scotia has created a new 40-page section on our website, [Transitions in Adult Care](#), or TiAC for short.

TiAC is intended as a one-stop caregiver source of help. The margin menu on the right is a representation of what you will see on our website under the Resources tab. Topics are arranged in order of increasing levels of intervention or service.

Throughout TiAC there are more than 100 linked documents from organizations such as Positive Aging, Continuing Care, Community Links, CAA, Housing NS, Pharmacy Association of NS, Legal Information Society of NS, Victorian Order of Nurses, and many more.

We have created a new province-wide list of private-pay housing options including assisted, supportive, independent and full nursing care facilities in Nova Scotia. Please contact us if you know of other facilities that could be added to this directory.

Another essential TiAC feature is the Caregiver Tips that appear with most topics. These purple text boxes contain both acknowledgements of the effort put into caregiving by family and friend caregivers and tools and strategies to keep caregivers themselves well. We repeat the message, "You are not alone" and encourage caregivers to contact us for further assistance.

During the next few months, we will be speaking with clinicians and groups throughout the province to increase their awareness of this resource and how it can benefit the caregivers of their patients and clients. Please help us spread the word and contact CNS if you need further information.

TiAC has been made possible by the Department of Seniors, Age-Friendly Communities Grant.

## Transitions in Adult Care

- Introduction
- What to Look For When Changes are Happening
  - Frailty
  - Mental Health
- Starting a Difficult Conversation
- Living Safely at Home
  - Medication Management
  - Nutrition, Hydration and Oral Care
  - Driving
  - Social and Recreation
  - Falls Prevention
  - In-home Monitoring
  - Home Care
  - Respite Care
  - Renovating to Age in Place
  - Finances and Legal Matters
  - Fraud
- Is It Time for a Move?
  - Downsizing
  - Moving in Together
  - Seniors Housing
  - Long-Term Care
    - Residential Care Facilities
    - Nursing Homes
  - Private-Pay Housing Options
- Crisis Care and Planning
  - Emergency Department Visits and Acute Care Stays
  - Adult Protection Services
  - Urgent Placement in Long-Term Care
  - Alternate Level of Care or Transitional Care Units

## Survivor Guilt

By Jennifer Briand, Western Region

Survivor guilt is the nagging guilt we feel after someone has passed, or a group of people have died, and yet we are alive and healthy.

Survivor guilt can take many different forms. In addition to the actual feelings of guilt noted above, feelings of numbness and thoughts about the meaning of life are common. Some people have difficulty sleeping and experience recurrent nightmares. Others withdraw from friends and social situations. Anger and irritability accompanying the survivor guilt are also frequent, as are flashbacks of events related to a loved one's illness or death.

Different types of experiences can lead to survivor guilt. Due to daily-reported tragic events in the media, for example, many of us experience at least transitory feelings of guilt. Constant attention to such devastating situations can become cumulative and produce a grief response which, in turn, may affect stress levels.

The sole survivor of a family that has perished in a crisis like a natural disaster or war often reports feeling guilty that they are alive when everyone else around them has been killed.

After hearing about a loved one's life-limiting diagnosis, survivor guilt can become a part of the grief process for family and friend caregivers. In recent decades, the nature of illness has evolved. People are living longer after diagnosis. Illness can be a long, winding, crisis-filled road. The caregiver often experiences survivor guilt when learning of the diagnosis, during the illness, and after their loved one has passed.

Survivor guilt can cause the caregiver to feel responsible for situations over which they have no control. I have, for example, often heard caregivers express their feelings of guilt in several ways.

"I should have done more."

"I could have been more present and spent more time with him."

"I should have taken her to the doctor sooner."

"I feel that I caused him stress at the end."

Does any of this sound familiar? Although these thoughts are real to the person expressing them, it's important to remember that they are not what caused your loved one's illness.

It is also perfectly normal to have feelings of 'wishing it were all over'; these feelings do not reflect lack of caring but instead of being overwhelmed. Remind yourself that you did all you could, and that you were a wonderful caregiver to your loved one.

My hope is that you find your way from guilt to comfort and healing! If you are experiencing survivor guilt, it helps to express your feelings in a supportive non-judgmental environment such as a Caregiver Support Group. For more information about caregiver support groups contact Caregivers Nova Scotia at our toll free number 1.877.488.7390.



## Hush, Hush Sweet Secrets

By Lynn Butler, Capital Region

Are you the keeper of your care recipient's secrets? Have you been sworn not to tell anyone about increasing health issues, a new and difficult diagnosis, where important legal papers are kept, or perhaps that none exist? Do you have to pretend that everything is business as usual, when it's not?

Not all personal matters need to be shared, and certainly not broadly. But there may come a time when for practical health or legal reasons it is important that certain facts be communicated to specific people. Keeping important information from others who should know because of a promise, can be stressful.

Many caregivers are not only the keepers of secrets but also of the anxiety that can come along with them. Caregivers may feel guilty that other family members, friends, or health care providers do not know how ill a person is or how difficult the care required at home has become. Caregivers may be worried that they will be blamed if there is a health crisis.

Some secret-keepers may live in fear that if they disclose information, they may be written out of the Will or removed as Substitute Decision Maker or Power-of-Attorney. The care recipient could decide to cut the caregiver out of future medical appointments, leaving the caregiver completely out of the loop. Keep in mind that many caregivers leave their paid work to give care to their loved one, so their position is risky if they are cut off financially or are asked to leave the home.

In my experience, keeping secrets can destroy relationships and cause suspicion and resentment among family members, potentially resulting in permanent damage to family relationships. But above all, keeping secrets can cause *you* to become ill.

The stress associated with keeping important information from others can lead to your own

poor health and can negatively affect your wellness. Elevated stress levels may contribute to high blood pressure, depression, anxiety, and a host of other physical and mental ailments.

You need to know that there may come a time when you need to share certain information in order to maintain your own sanity and put proper medical or legal plans in place for your care recipient. It won't be easy, but it may become a necessity.

How can one press the restart button and turn things around? Initially, you can try discussing the situation with your care recipient, a little at a time. Explain how keeping certain information from others is affecting you, how it makes you feel anxious or dishonest. Try to get your loved one to understand the importance of opening up about information that is causing you stress and putting their own health at risk. It might be advisable to ask a professional to help with this conversation: your family doctor, an elder mediator, clergy, lawyer, or mental health clinician may be able to offer assistance.

When asked to keep a secret, be honest and tell the person that you will guard this information as long as it is possible and safe to do so. Should there be a time, however, when it needs to be told, you may have to do just that. The only way to avoid this situation is to never make a promise to keep secrets no matter what the circumstances. You may feel honoured that you are the one your care recipient trusts enough to share information with, but it can very quickly become a burden.



### ***Got feedback?***

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

Contact us.

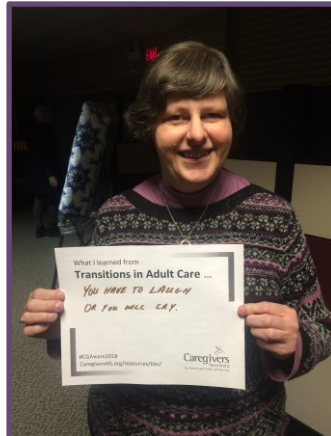
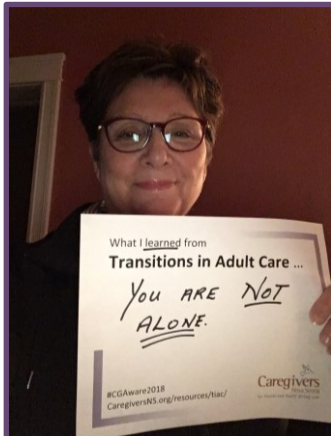
## Support Group members share what they learned from Transitions in Adult Care (TiAC) and how it made them feel.



*The Long term care checklist!*

*Caregiving continues in LTC.*

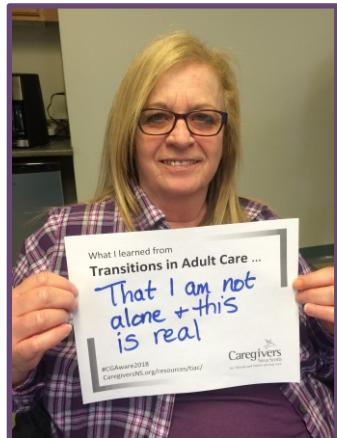
*An excellent source of information and help.*



*Always have a Plan B; don't take your freedom for granted.*

*You are not alone.*

*You have to laugh or you will cry.*



*That I am not alone & this is real.*

*I did not know it would be so difficult.*

*It isn't what I thought it would be. It's hard. ☹️*

## Introducing TiAC

A new addition to our website providing one-stop caregiver support

What could you learn from Transitions in Adult Care?

<http://www.CaregiversNS.org/resources/tiac/>