

The Beacon

Spring/Summer 2017



In this issue...

Vaccinations	2
Forgiveness	3
“Informal” Caregiver	4
Fidget Mats	5
Carrot Cake Recipe	5
What a Difference a Day Makes	6
Tales from the Other Side	7
Support Group Directory	8

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#CGAware2017

In Nova Scotia May is Caregiver Awareness Month which is also celebrated in British Columbia and Alberta. It is important that we acknowledge the contributions of unpaid family and friend caregivers to Canadian society: they deliver 10 times as many hours of care as paid care providers, for an estimated savings of \$66 Billion.

Join us in recognizing the contributions of our province’s many caregivers. Participate in our awareness campaign, known in the social media world as #CGAware2017. Every day in May will hold something exciting, and our website will feature a new page created especially for Caregiver Awareness Month which will go live May 1. Please visit often!

To mark Caregiver Awareness Month, Caregivers Nova Scotia has invited provincial MPs and MLAs to show their support by meeting with a caregiver. As well, libraries across the province have created lists of resources related to caregiving. Some branches will also display important messages on their monitors.

Without caregivers, many loved ones could not remain at home or receive the additional care they may require in facilities. Supporting caregivers can be as simple as dropping off some baking, reaching out to a caregiver who may be feeling isolated with an offer of assistance, or by just listening without judgment.

Our Annual General Meeting
will be held on
Saturday, June 10th - 11:00am at the
Halifax Central Library,
Creative Lab, 2nd Floor,
5440 Spring Garden Rd (at Queen St)
Please RSVP to our toll-free # below.

Caregivers deserve the recognition and support of all Nova Scotians.

Angus Campbell,
Executive Director



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



for friends and family giving care

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Vaccinations

By Maggie Roach-Ganaway, Support Coordinator, Cape Breton Region

Hearing the recent news stories of the resurgence of childhood diseases that vaccination could have prevented, I began to think about adult vaccines that sometimes get overlooked. Having worked in health care for many years as an LPN, I thought people may be interested to know about some of the vaccines that the College of Family Physicians of Canada and Immunize Canada are recommending for people aged 50 and older.

1. **Influenza Vaccine:** A yearly dose is recommended for older adults, especially those with chronic conditions. Side effects can include soreness or swelling at the injection site, hoarseness, red or itchy eyes, cough, fever, aches, headache, and fatigue. These effects usually only last a day or two and are not usually serious. Contraindications (reasons to avoid the vaccine) include a fever, allergy to eggs, or a severe reaction in the past.
2. **MMR (Measles, Mumps and Rubella) Vaccine:** People born before 1956 may not have had this vaccine, and anyone who didn't have one of these childhood diseases may need a booster shot. Women who are, or are trying to get, pregnant should avoid this vaccine, as should anyone with cancer or undergoing cancer treatments, or who has an allergy to gelatin or neomycin.
3. **TDaP (Tetanus, Diphtheria and Pertussis) and TD (Tetanus/Diphtheria):** Those who have never received the TDaP vaccine should receive it at least once as an adult; this is particularly important for people who come into close contact with children younger than 12 months. Booster shots are required every 10 years. Side effects may include soreness at injection site and, in some cases, an allergic reaction. Consult your doctor if you have epilepsy, have had GBS, or had severe swelling or pain from a previous dose.
4. **Herpes Zoster (Shingles) Vaccine:** Anyone who has had chicken pox is at risk of shingles, a painful, blistering skin rash; this vaccine can lessen the effects. Only one dose is needed. Anyone with an allergy to gelatin, the antibiotic neomycin, or to any other component of the vaccine should avoid this vaccine, as well as those with weakened immune systems or who are taking steroids.
5. **Pneumococcal (Pneumonia) Vaccine:** Everyone over the age of 65 and people over 50 who have specific risk factors should receive this vaccine. Only one dose is needed, but for individuals with asthma, COPD, heart disease, diabetes, leukemia, lymphoma, or smokers who are at high risk of invasive pneumococcal disease this vaccine can be lifesaving.
6. **Hepatitis A and B Vaccines:** People who travel to locations with a high incidence of Hep A & B should consider this vaccination. Hep A vaccine is given in 2 doses (0 & 6 months), while Hep B is given with 3 doses (0, 1 & 6 months). Contraindications include an allergy to yeast, an allergic reaction to a previous dose, or being moderately ill at time of dose.

Please keep in mind this is for information only; it is important to talk to your family physician about whether you are a candidate for any of these vaccines.



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.

Forgiveness

By Cindie Smith, Support Coordinator, Northern & Eastern Mainland Region

During private conversations and in Support Group settings, caregivers sometimes talk about deep feelings of hurt and bitterness. These feelings are often associated with unkind remarks, undeserved judgement, being taken for granted, or being abused. The injury is usually close to the surface, even many years later, and we quickly become emotional when retelling the story of the incident as if the episode has just occurred. It becomes obvious that we have not healed from being wronged.

Forgiveness is important for a couple of reasons. First, few caregivers have the luxury of extra emotional energy to expend on replaying the incident over and over. Secondly, the person who has wronged us may not even be aware of our feelings. This may be a burden we alone feel, and as a result it may be increasing our stress and damaging our emotional and physical health.

Everett Worthington, a researcher at Virginia Commonwealth University in Richmond, has developed an interesting procedure to guide us through the healing process of forgiving.

REACH Forgiveness of Others

www.evworthington-forgiveness.com/reach-forgiveness-of-others/

R – Recall the hurt. To heal, you have to face the fact that you’ve been hurt. Make up your mind not to be nasty, not to treat yourself like a victim, and not to treat the person as a jerk. Make the decision to forgive. Decide that you are not going to pursue payback.

E – Empathize with your partner. Empathy is putting yourself in the other person’s chair. Pretend that the other person is in an empty chair across from you. Talk to him. Pour your heart out. Then, when you’ve had your say, sit in his chair. Talk back to the imaginary you in a way that helps you see why the other person might have wronged you. This builds empathy, and, even if you can’t empathize, you might feel more sympathy, compassion, or love, which helps you heal from hurt. This allows you to give an ...

A – Altruistic gift. Giving forgiveness is an unselfish, altruistic gift. We all can remember when we wronged someone—maybe a parent, teacher, or friend—and the person forgave us. We felt light and free. And we didn’t want to disappoint that person by doing wrong again. By forgiving unselfishly, you can give that same gift to someone who hurt you.

C – Commit. Once you’ve forgiven, write a note to yourself – something as simple as, “Today, I forgave (person’s name) for hurting me.” This helps your forgiveness last.

H – Hold onto forgiveness. We write notes of commitment because we will almost surely be tempted to doubt that we really forgave. We can re-read our notes. We did forgive.

Most importantly, we need to forgive ourselves. For all the things that didn’t get done, the things that weren’t done as well as we would have liked, for the negative self-talk, for the failures, for the unintended sharp words, for wanting out, for being unable to speak up for ourselves, for longing for the life we thought we would have ... we feel that we are undeserving of forgiveness. A separate 6-step process for forgiving ourselves can be found at www.evworthington-forgiveness.com/six-steps-to-forgiving-yourself. If you are not online, perhaps someone at the library could print this for you.

Forgiving doesn’t mean that we won’t still feel the hurt of being wronged, but it does mean that it won’t overshadow all the good aspects of our lives.

“Informal” Caregiver

By Lynn Butler, Support Coordinator, Capital District

At Caregivers Nova Scotia, we are sensitive to the use of language when it comes to caregiving. The caregivers with whom we deal tell us that words *do* matter, that it is important to them that the way others describe what they do makes a real difference between feeling validated or demeaned in the demanding responsibilities they have taken on.

One term caregivers particularly dislike is “informal caregiver”. This term is sometimes used by people in professional fields. The implication, caregivers tell us, is that they are “just” family, friends, neighbours, or other well-meaning folk who provide “informal support” or “informal care”. It is the doctors, nurses, occupational therapists, physiotherapists, social workers, and home care workers who are paid for their services who provide the “formal” (that is, the “real” support).

Those who use the term “informal caregiver” are no doubt doing so with no intent of insult, but we would ask them to think about how the phrase is perceived by caregivers. How do they perceive the work that they do? How many of them would refer to the work they do, the duties and tasks they perform, and the responsibilities they have as “informal support”?

Caregivers quickly become expert at providing care to their loved ones. Most soon become well educated about the disease or health condition of their care recipient, be it frailty, cerebral palsy, Parkinson’s, MS, dementia, cancer, or any of a myriad of other disorders. Caregivers know their loved one better than anyone else including the activities with which they may need extra help and support.

Caregivers organize complex care and medication routines. They talk with a range of professionals, including physicians and pharmacists, to better understand the health conditions and learn what exactly needs to be done. They work alongside homecare workers, assisting and orienting them to the unique challenges of their care recipient’s case. Caregivers frequently research community and government supports, and they may even be searching for clinical trial opportunities. It is caregivers who are the first responders in a crisis. It is typically they who recognize when something isn’t right and that immediate attention is needed.

The responsibilities and duties of caregivers are anything but informal. How can we begin the process of banishing a term that offends the people on whom we, as a society, are so dependent? Let’s start by recognizing the extraordinary service they provide to the country. At last count—in 2012—there were over 8 million Canadians, family and friends, who gave care to another person dealing with a chronic or acute physical or mental health condition or with aging related problems. Without unpaid caregivers, the health care system in this country could probably not function: it is unsustainable without them.

So the next time any of us starts to speak the words “informal caregiver” or “informal support”, let’s stop and think how would the caregiver likely respond. What term best shows the value we place on their indispensable efforts, only essential for their care recipient but invaluable to Canada as a whole? So, let’s all adopt the phrase caregivers prefer: family and friend caregiver.

Fidget Mats

By Brenda Sangster, Support Coordinator,
Capital District

Have you ever noticed someone with dementia who appears restless, lost, and unable to settle? While watching care centre residents fidget, Marcia Engquist, a designer of activity aids for people with dementia, began to think about ways to reduce such behaviour. The Fidget Mat was born.

We all feel the need to be productive. And holding tools such as clothespins, house keys, nuts, bolts and washers, a measuring tape, a wallet, or sandpaper can be calming. Buttoning clothes, zipping zippers, snapping snaps, and tying ribbon can bring someone with dementia back to the days of dressing their children for school. The feel of these items can be comforting and lift spirits as motor memory reminds them they are familiar. And the exercise of fingers and hands is beneficial.

Fidget mats are designed to reduce agitation by keeping a person's hands busy while occupying their mind. These colourful mats can stimulate our loved one with dementia, autism, or who are recovering from strokes. At a time when simple repetitive movements and sensory experiences become more important, fidget mats can provide safe means of comfort.



One of the fidget mats kindly donated to Caregivers Nova Scotia by Carolyn Sparling.

You can customize the mat to the interests of your loved one. It can include satin, suede, strings, beads, colours, pockets, squeakers, yarn, soft toys, or furry pockets. Remember to keep safety in mind and secure items to withstand constant pulling and washing when needed. Your creativity need not be restricted to a mat but can expand to a quilt, cushions, an apron or a hand muff.

A fidget mat can provide topics of conversation for both caregivers and staff. They can also give your loved one something on which to focus and as a result you may receive some much-needed respite, even if only for a few minutes.

You may find other ideas for fidget items at www.patchworkposse.com/fidget-quilts/

Dad's Favourite Carrot Cake

from Jennifer Briand

2 cups of unbleached flour
1 cup light olive oil
1 cup of organic brown sugar
4 fresh large eggs
2 tsp soda
2 tsp cinnamon
1 tsp baking powder
pinch of cloves and nutmeg
1 tsp salt
3 cups grated carrots (new is best)
¾ cup walnuts



Mix all dry ingredients together. Add oil, eggs, and grated carrots mixing well after each one. Batter will be quite thick. Bake at 350 degrees for 55 minutes. When you remove cake let it settle for about 10 minutes then remove from pan.

Cream Cheese Icing - Cream one 8oz pkg of cream cheese with ½ cup of butter. Add 2 tsp of vanilla and 6 cups (750 g) icing sugar. Spread on cake once it has cooled. Let
5
icing set for at least half an hour before serving.

What a Difference a Day Makes

By Carlye Stein, Research and Operations Coordinator

Imagine you are members of a non-profit organization, and you suddenly find yourself in a room with 16 of Nova Scotia's top minds in marketing, digital media, fundraising, and corporate business strategy (think vice-president and COO of NSLC). Those minds are dedicated *exclusively* to you for an entire day, to help your organization wherever its greatest needs lie. Their collective hourly consultation fee would be in the thousands. But for you, on this day, their services are FREE.



For Caregivers Nova Scotia, this dream day became a reality thanks to an organization called [The Give Agency](#). In their words, *"The Give Agency was created by three 'ideas' people - a Creative Director, a PR & Communications Strategist, and a Filmmaker and Corporate Strategist, as a meaningful way for Halifax's top idea rockstars to put their expertise to work for nonprofits."*

In February, Caregivers Nova Scotia applied to become a Give Agency client. We were one of five agencies in Nova Scotia to be selected. Two CNS Board members (James McRae and Kathleen Robertson), Angus, and I joined our Volunteer Givers (the 'rockstars') on March 10th. We met in a sun-filled room on the fourth floor of the new Discovery Centre in downtown Halifax.

The day that unfolded was magical. After an initial Q&A with Angus about who we are and what we do, we broke into three large groups. Angus and I were each in a group, and James and Kathleen were in the other. Each group focused on one of three topic areas: Individuals, Government, and Corporate. We talked about strategies that CNS could use to engage with audiences in these areas to help us raise awareness, increase the number of clients we support, and increase funding.

By the end of the day, there was a wall of whiteboards, several giant pink post-it notes, and three flipcharts all filled with hundreds of ideas.

Within a few days, The Give Agency organizers had distilled everything down into an Action Plan for us. The Plan captures the top ideas from the day, prioritizes them, and outlines how CNS can put them into place. This information is incredibly valuable, and I'm sure we will return to it again and again for inspiration and guidance.

The Give Agency Day was an incredible opportunity, and we are so grateful to everyone for their help. Just so you know, some of the ideas from that day will come to life during Caregiver Awareness Month, so stay tuned!

Tales from the Other Side

By Jennifer Briand, Support Coordinator, Western Region

When a loved one is diagnosed with a life limiting illness or disability, the person who has just become the caregiver assumes a long-term responsibility. This sudden shift can be difficult and can alter the caregiver's life substantially. But what about the care recipient whose life has also just changed dramatically? Although everyone has their own individual needs, there are a few things that everyone wants, or doesn't want, from their caregiver.

Everyone Wants to be Heard. Caregivers often focus on the needs of their loved ones and on tasks essential for their health and comfort. They may "take charge", which both helps deal with their own mixed emotions and provides momentum for the new role. This 'bulldozer attitude' may be resented by the care recipient and can result in missed opportunities to communicate or comfort the loved one, who may need a shoulder to cry on or someone to just listen. When they complain about pain or feelings of depression, your first instinct may be to help by running to the drug store for medication or to say "let's go out to visit some friends". Yet such activities may not be what your loved one needs in the moment. Try saying, "I'm sorry that you're having such a rough day" or "Can you tell me more about why you're feeling down?" Such statements show that you care, and that you are listening. It's important to maintain open communication with your loved one and to remember they will feel different and communication will change as their disease progresses.

People Don't Want to be a Burden. Care recipients are dealing with feelings of losing control, as their roles shift and their spouse, child, parent, or friend becomes their caregiver. 'Joan', for example, is caring for

her mom, who has advanced heart disease. She still lives in her own home, and Joan visits her daily. While bringing dinner, Joan lists items she wants to discuss with her mother about her living situation and the state of her home. Her mother simply replies, with a sigh, "Yes, mama", conveying a message of her concern regarding their switch of roles and her own feelings of helplessness. Had Joan said instead, "How can I best help you today, Mom?", the response may have been better, with her mother feeling that she had some control over her situation. She might well have revealed more about her feelings that day.

Diagnosis of a serious or progressive illness leaves your loved one feeling vulnerable. They don't want to become a burden, especially if they are used to caring for everyone else. They don't want to lose their independence, become a financial burden, or take up their family's time and energy. Remember while it may be important to work on practical activities, such as paying the bills or fixing the house to sell, you need to be sensitive. Watching someone else plan one's life can be traumatic. Your loved one wants to believe that he or she will continue to be a contributing member of the family. Experts agree that this is consistent across all age groups and cultures.

Have you ever wondered ...

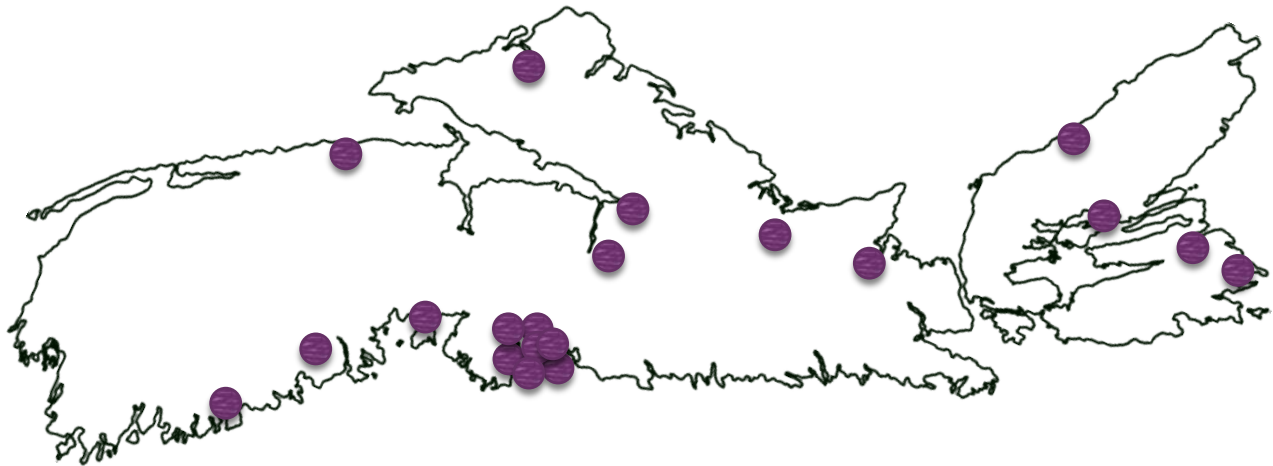
- *How do I plan for future healthcare when I am not sure what my needs will be?*
- *What qualities do I look for in a substitute decision maker?*
- *What are the main values and beliefs that shape my quality of life?*

... our workshop on **Advance Care Planning: Getting Started** can help.
Learn more by calling **1.877.488.7390**.

CNS Caregiver Support Groups in Nova Scotia

Because no one understands a caregiver like another caregiver.

We facilitate 21 Caregiver Support Groups each month across the province. Our Support Group meetings are not specific to any one particular disease; as such, we are able to focus on the needs of the caregiver rather than a medical condition. We respect and value all caregivers and all caregiving situations. Our meetings are confidential and you are only asked to share to your level of comfort. If you want to just sit and listen, that's okay too. A complete listing of meeting dates, times and locations can be found on our [website](#), or by contacting our office at 1.877.488.7390 or Info@CaregiversNS.org for more information.



Group members have told us ...

"This group is a port in the storm!"

"I am able to share feelings I can't share anywhere else."

"I now know others go through the same experiences."

"... feeling that I am not alone, having support, and being able to speak openly."

"... realizing that I am doing a few things right, gaining confidence from the support of others"

Caregiver TeleGroup

Caregivers Nova Scotia also offers a telephone-based Support Group twice each month. This is ideal for caregivers who cannot step away from their situation, have limited access to transportation or respite, or who do not have an in-person Caregiver Support Group in their area. Support is as easy as dialing a toll-free number!

Please contact our office for more details by calling 1.877.488.7390 or emailing Info@CaregiversNS.org

