

The Beacon

Fall/Winter 2014



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

Greetings from Angus Campbell, Executive Director

Welcome to our third issue of *The Beacon*. When I reflect back on our accomplishments since our first issue, I am happy to report that Caregivers Nova Scotia continues to expand our supportive services and outreach to family and friend caregivers throughout the province.

From April to September we had 2,256 caregiver contacts with support calls, support groups, and educational workshops. We also attended five health fairs and made 27 presentations to 487 health care providers, caregivers, and community organizations.

During that time our monthly in-person support groups have increased from 12 to 17. Additionally, we are piloting a research project on telephone support groups. The early results look promising, and this type of meeting could be very useful for caregivers who are unable to travel to support groups.

Caregivers Nova Scotia is committed to the Nova Scotia Dementia Strategy development by sitting on the Advisory Committee, participating in the Families and Care Partners Working Group, and holding Dementia Conversations with our support groups in November.

And we are also committed to you – our caregivers, partners, and allies. We are currently surveying our support groups for feedback, and we pay attention to workshop evaluations. I thank you for taking the time to complete them.

On behalf of the Board and Staff of Caregivers Nova Scotia, I wish you Happy Holidays and all the very best for 2015.



for friends and family giving care

3433 Dutch Village Road, Halifax, NS B3N 2S7
Tel. 902.421.7390 | Toll-free 1.877.488.7390

Info@CaregiversNS.org www.CaregiversNS.org

The Benefits of Pet Therapy

By Brenda Sangster, Caregiver Support Coordinator, Capital District

As caregivers, it is so important to take care of ourselves, and having a pet can be a great way to relieve stress. Did you know that having a pet may decrease your blood pressure, provide companionship, help you meet new people, reduce anxiety, and add structure and routine to your day?

Stroking, holding, cuddling, or touching an animal can calm and soothe us. They are a source of love and friendship and can actually make us healthier. Many studies have shown that having a pet can help us live longer and can also help us cope better during difficult times.

When considering a pet it is important to think about your level of activity. Is most of your time spent at home? Are you very active? Who else is in your family (are there children, are you caring for an ageing relative)? Are there other pets? What is your home environment like? What time commitment can you make?

For our family, the right choice for us was to have a cat. Her name is Lulu and she is an indoor cat. We don't have to worry about her wandering off. She was very easy to train.



Lulu

She is fiercely independent. She is also a great companion to my 83-year old mother. When I come home at the end of the day, I look forward to Lulu greeting me at the door. She stretches out so I can rub her belly -- and expects it!

On the other hand, my co-worker Lynn has a dog named Winnie. A dog is a better choice for Lynn's family. They have grown children, are very active, and live in an area that has lots of places for Winnie to exercise and play. Lynn will often bring Winnie to work, and we feel she is a great addition to our office.



Winnie

Consider adding a pet to your family! Owning a pet has been known to lessen stress, and they do offer their owners unconditional love.

1.877.488.7390

Do you have a friend or relative who is struggling with the physical and emotional demands of giving unpaid care to a loved one? Please suggest they give us a call. All our services and programs are free. No referral needed!

How to say “No” (and not feel guilty)

By Lynn Butler, Caregiver Support Coordinator, Capital District

How do caregivers know when they have reached the point where they can no longer manage to provide care? How can a caregiver set limits on the care they give without feeling guilty? What signs might indicate caregiving responsibilities are becoming overwhelming?

These are questions that most caregivers do not give much thought to until they are almost at the end of their rope. Finding a way to say, “No, I alone am no longer able to provide this level of care”, may actually prevent caregiver burnout. It may even open up new opportunities to share the caregiving experience with others.

“No” is not a word in most caregivers’ vocabulary. However, it is a word that many of us need to get more comfortable using. Saying “No” does not mean that you are harsh or uncaring. It simply means you have boundaries and are caring for yourself by not taking on more than you can manage. If you have begun to notice that you are angry, fatigued, depressed, in poor health, or if you are just feeling like you cannot see any light at the end of the tunnel, you need to take action. One action you can try is to learn to say “No”.

There is a simple but effective communication strategy that can help caregivers set new and healthy boundaries. Try speaking from an “I” point of view. For example, “I can no longer drive you to all of your medical appointments. I am just not able to take more time off from work. I know this is a change for you but I will look into other options. Mary has offered to take you on several occasions, so I will ask her if the offer still stands.”

Make sure that when you use this approach you clearly present what you are no longer able to do, acknowledge that this is a change for the care recipient, and suggest a possible solution.

Start small and see what happens. I guarantee that life, as you and your care recipient know it, will not end. In fact, it just might get better.

Angus’ Pots de Crème (serves 4-5)

Looking to keep chocolate lovers happy during the holidays? This is a delicious but very quick and easy variation of the 17th century French dessert. Bon appétit!

Ingredients

- 1 ¼ cup coffee cream
- 1 cup good quality chocolate chips
- 2 egg yolks
- 3 tbsp brandy or orange liqueur (or 2 tbsp orange juice with 2 tsp orange zest)
- Optional garnish of berries such as raspberries or blackberries, or mint.

Bring the cream just to a boil. In the meantime, place chocolate, brandy or liqueur (or orange juice and zest), and egg yolks in a blender. Add the hot cream and blend at high speed until thoroughly mixed. Pour into tall dessert glasses or ceramic pots. Chill in the refrigerator uncovered for at least three hours (and preferably more). Top with fresh raspberries or blackberries or mint.



The Stages of Caregiving: Stage 2 – Recreating Your New Normal

By Jennifer Briand, Caregiver Support Coordinator, Western Region

You didn't really have time to digest exactly how life was about to change when you first heard the news that changed everything, the news which led you to the caregiver role that has become your 'new' normal. As a caregiver, you have already been through all of the hospital stays and discharges, short rehabs, and the endless cycle of health professionals whose advice may have confused you at first. Now you are the caregiver who strives to find solutions and balance. While the reality of the condition facing your loved one settled in your mind quite quickly. It often takes much longer, months or years, before you realize how much your life has been transformed by this experience.

This stage of the caregiving journey can prove to be both the most difficult and yet the most rewarding for the caregiver. On one hand you want to care for your person; you feel it's the right thing to do, whether out of a sense of duty, love, or expectation. On the other hand, you may feel exhausted by your extra duties, your lack of social activity, or you may have had to quit your job. It may even be difficult to imagine what your future holds. The internal struggle may cause a caregiver to feel fear, anger, resentment, or apathy. Emotional instability can become the hallmark of this stage, leading to caregiver burnout. The caregiver may choose to make positive changes in his or her lifestyle and approach to caregiving.

If you are able to find a balance, it can enrich your caregiving experience and empower you to lead a much more fulfilling life at this stage.

So why do caregivers decide to commit themselves to such a precarious journey? One of the caregivers in our support groups said it eloquently; *"It is what it is! Providing care for my husband helps us both deal with this debilitating disease. I am gradually coming to terms with our situation, and helping him gives me an inner strength I didn't realize was there. I am still learning to make caregiving part of, but not all that I am. Most of all, this experience has provided me with hope for the future."*

I have noted several qualities that are typical of a caregiver during this stage;

- Caregivers are **caring** and **loving** people; which shines through during this time.
- **Protective**: many caregivers feel very strongly about protecting their loved ones.
- **Perfection**: they have a strong need to keep things the same, or adjust to make it almost the same, even as everything is changing around them.
- **Fix it attitude**: especially in the face of a progressive illness.
- **Tenacity**: they have what it takes to stick with it, and do what needs to be done.
- **Resilient**: they have the ability to bounce back from whatever happens, or doesn't happen.
- **Hopeful**: this quality keeps them motivated and in it for the long haul.

During this stage of your caregiving journey, remember to make caregiving part, but not all, of who you are. Your new normal may continue to change, and may not be what you had planned for the future, but it is yours. Embrace it!



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

Five Potential New Year's Resolutions for Caregivers

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

The final weeks of 2014 are upon us. It's that season when many people begin to ponder the resolutions they might make for the coming year. All worthwhile New Year's resolutions are difficult to put into effect successfully, but it's a good idea for everyone to adopt ideals that will give meaning and focus to their choices and activities. As caregivers, the reality of our lives is in some ways different than that of others. What New Year's Resolutions might make most sense for us to consider?

1. I will take care of my mental and physical health. Caregiving brings me many rewards. It is also demanding and can take a toll on my health, both physical and mental. I know that stress and depression are known contributing factors to illness. If I am not healthy I cannot take care of my loved one. I will strive to take care of my own health.

2. I will offer respect but also insist firmly on being treated with respect. I deserve respect from my care receiver, and from other family members, friends, and health care providers. While knowing that dementia will affect a person's behaviour, I'll also keep in mind that, when challenged, they may sometimes understand enough to change their behaviour for a time. I will calmly state to anyone who verbally abuses me that I do not allow anyone to treat me that way, and I will remove myself from the situation.

3. I will ask for help with caregiving if I need it. I will remember that if I need to leave a situation where I am being verbally or physically misused, I will seek respite or in-home care. If my loved one is in Long Term Care, I will alert the staff that I need to take a break.

4. I will remember that getting help is not a failure on my part. I realize that I sometimes

feel that I should be able to provide everything my care recipient needs. I have to recognize that there will be times when my loved one requires more help and specialized care than I can safely provide. Physicians, other health care professionals, in-home care, and Long Term Care all can and should help to take care of my loved one. I will give myself permission to accept help without guilt.

5. I will work in partnership with the professionals caring for my loved one. I want the best care possible for my loved one. Nonetheless, I will not let my passion for good care create an adversarial atmosphere with the professionals who provide care. I will remember I am my loved one's advocate but will also remember that most advocacies involve diplomacy. Partnerships create the right balance.



Tips for Caregivers

Dialing 8-1-1 gives you access to non-emergency health information and services. You will speak to a registered nurse who can provide advice, information, and reassurance about a number of general health issues.

Tips for Caregivers:

1. Be at the care recipient's residence when you call.
2. State that you are the person's primary caregiver.
3. You will likely be asked to go to your care recipient's side so that the nurse can ask you questions that will help her/him to understand and assess your care recipient's condition.

For more information, visit 811.novascotia.ca

How Research Can Improve Caregivers' Lives

By Carlye Stein, Research and Operations Coordinator

Research informs many aspects of Caregivers Nova Scotia's (CNS) work, from the information in *The Caregivers Handbook*, to the content of our website, to the facts and figures we present in our educational workshops. We not only engage in this type of secondary research, which involves collecting and summarizing information from existing sources, we also engage in primary research, where data are collected from participants.

One of the primary research studies we are involved in is the Caregiver Tele-Group Support (CTGS) pilot project, led by Dr. Grace Warner of Dalhousie University's School of Occupational Therapy. The study is looking at the potential benefits of holding support group meetings over the phone for caregivers who cannot attend in person due to lack of transportation (especially from rural and remote areas), mobility issues, or because they are unable to leave their care recipient.

We know from existing research that support groups provide a means for participants to exchange knowledge and ideas, receive emotional support, and help one another to reduce caregiver isolation. Support groups have also been shown both to reduce stress and to increase caregiver confidence. This evidence base provides a strong argument for the need to offer support in alternative formats such as tele-groups.

The other primary research study we are currently involved in is called CARE, which stands for Care and Respect for Elders in Emergencies. Dr. Stacy Ackroyd, an affiliated scientist with the Department of Emergency Medicine at the Halifax Infirmary, is leading this study. The study seeks to learn more about older patients' experiences in the emergency department and to find out what is most

important to older patients and their caregivers when they visit. CNS has recruited participants and will assist with interpreting the data and customizing the program for a Nova Scotia context.

The CARE program has already been successfully implemented in a New York City hospital, where volunteers were trained to provide additional support and activities for older patients that emergency department staff don't usually have time for, such as sitting with a patient or reading to them. The potential benefits of the study for Nova Scotians include improvements in emergency departments that will help make the experience more comfortable and less stressful for older patients and their caregivers.

We look forward to the completion of both of these studies, and to learn just how this research will translate into better care. We hope the results will also help CNS to improve and possibly expand our services for caregivers throughout the province.



If you have spare teacups and saucers and would consider donating them for our Caregiver Appreciation Teas each May, please call our Halifax office at 902.421.7390 or toll-free 1.877.488.7390.

Dear Santa: All I want for Christmas is ...

By Cindie Smith, Caregiver Support Coordinator, Northern and Eastern Mainland Region

It's time for the question many of us dread ... "What would you like for Christmas?" Some of us have received odd gifts, perhaps items we didn't really like, need or want. But yet we continue to respond, "Oh, nothing!" or "Anything would be fine." It is not in our caregiving nature to state our wishes or needs, but we ought to recognize that to a great degree we can be in the driver's seat with gift suggestions.

Let's take a practical approach because you will probably be asked by someone, "What would you like for the holidays?" Put the list below (or make up one of your own) in an envelope marked **WISH LIST** on the fridge and share it with anyone who asks you. You deserve a real gift!

----- CUT ON DOTTED LINE -----

If you are reading this, you have asked what I would like as a Christmas gift. Please consider a gift from the list below which has been suggested by *Caregivers Nova Scotia*, or use it as inspiration for a different gift. Thanks for being so thoughtful!

Free or low cost gifts

1. A mixed CD of some of my favourite music for a home-made concert
2. Shoveling snow from the step and walkway for a month or for the whole winter
3. Running errands for a week or month - groceries, pharmacy, etc.
4. Write a list of the things I do well as a caregiver for days when I need encouragement
5. Call to see how I am doing once a week
6. Make frozen meals – make a little extra as you cook for your family and freeze some for us
7. Baked treats – again, make a little extra and freeze
8. An overnight stay while I am home – your ears listen so mine can sleep
9. Make a list of local library books about caregiving and my loved one's health condition
10. Write down your favourite memories of my loved one
11. Read about my loved one's health condition so you understand our situation
12. On the really hard days, listen without judgment even if I say ridiculous things
13. Visit with my loved one so they will have company, even when I am home
14. Other _____
15. Other _____

Gifts for purchase

1. Two hours of maid service
2. An in-home foot care service
3. An inspirational book
4. A few hours of respite care
5. An emergency crank radio/flashlight
6. Fancy, flavoured tea or coffee for a treat without leaving home
7. A donation to a non-profit organization that is important to me
8. Other _____
9. Other _____



Wishing you all the joy of the Holiday Season!

Angus



Brenda



Lynn



Jennifer



Cindie



Carlye



Winnie



Maggie



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