The Beacon

Fall/Winter 2016

In this issue…

Board of Directors

Message from the Executive Director

In May I was invited to testify before the Senate of Canada's Committee on Social Affairs, Science and Technology which was examining and reporting on the issue of dementia in Canada. The Committee's focus on this issue was in part prompted by predictions that, with Canada's aging population, the toll taken by the disease on the population and economy may double over the next fifteen years.

The Committee Chair is Senator Kelvin Ogilvie, a native Nova Scotian, who served as President of his alma mater Acadia University from 1993 to 2003. In introducing Caregivers Nova Scotia (CNS) and me, Dr. Ogilvie commented on the quality of our website, noting the amount of useful information to be found there, the clarity of the presentation, and the ease of navigating the site.

Although CNS was the only caregiving organization invited to appear before the Committee, I felt it was important to try and represent other groups with a similar focus, to ensure that as many caregiver perspectives as possible were included.

Those appearing before the Committee were invited to provide a written submission as well as make an oral presentation to the Committee. In addition to describing who CNS is and what we do, I outlined the unique support currently provided to families by the provincial government (the Caregiver Benefit, the Supportive Care Program, and funding for our organization).

While noting the extraordinary levels of caregiver willingness, capacity, and readiness to help, I also pointed out that for people

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

Caregivers Nova Scotia
for friends and family giving care

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Message from the Executive Director

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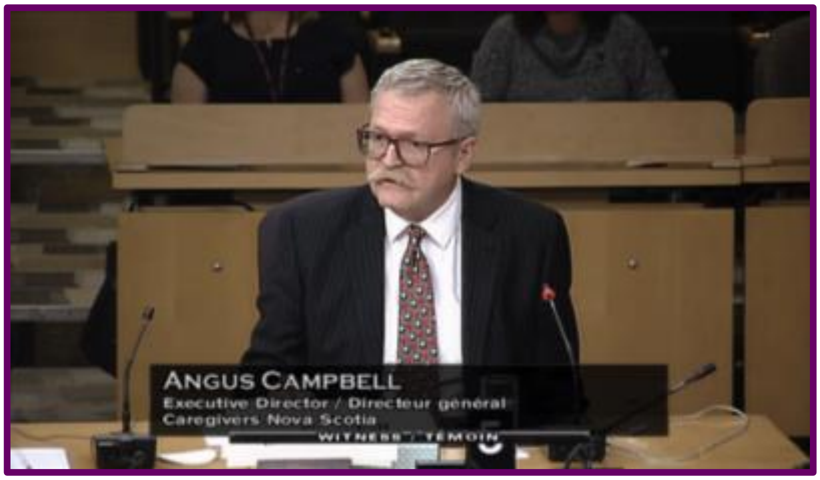

to be able to continue to give the assistance that will enable their loved ones to remain at home, it is critical that caregivers be provided with appropriate support. In my recommendations to the Committee, therefore, I stressed the importance of establishing contact with family and friend caregivers early in their caregiving journey, of respite care, and of referral to caregiving programs.

In its report, the Senate Committee similarly noted that as many as 90% of those with dementia live in their own homes, but this is only possible with the proper supports. Among the Committee's recommendations to the government is the suggestion to establish immediately the Canadian Partnership to Address Dementia, with a mandate to create and implement a National Dementia Strategy. Included in this broad partnership would be health-related organizations, caregivers and care recipients.

It was an honour to have been invited to appear before the Senate's Committee on Social Affairs, Science and Technology, and I wanted to ensure that I could echo many sentiments and challenges caregivers experience. To read the full report, go to caregiversns.org/news. A link to it can be found in the news item dated November 29, 2016.

Angus Campbell, Executive Director

These are our wishes for clients
and colleagues in supporting caregivers …

Resilience Comfort Serenity
Cheer Strength Self-compassion Hope

The Staff and Board of Directors of Caregivers Nova Scotia
wishes you and yours all the best in 2017.

Long-distance daughter

By Carlye Stein, Research & Operations Coordinator

My parents have supported my every move: to Spain, then England, and now Canada. I have lived away from them for more years than I ever lived with them. They have never begrudged my need to explore, to be elsewhere. But thousands of miles means I can't stop by on my way home from work, or plan a weekend trip to visit them when I want or need, or when they want, or need.

Admittedly, I did not plan my relocations with aging or ill or caregiving parents in mind. So as my mom's caregiving journey with my dad has unfolded, I have only been able to help from a distance. When I am able to visit, I do all I can: shop, run errands, give my mom respite, help my dad with whatever he needs, physically or emotionally. It never feels like enough, but it does feel concrete and meaningful.

In the countless hours between visits, guilt, frustration, sadness, all compete for my attention. As my dad's condition becomes more complex and more fragile, I feel more and more helpless. And with respect to emergencies, what I can do is always too little, too late.

As a long-distance daughter, I've struggled to define my role with respect to caregiving. In a recent conversation with my mom however, I found one answer. My mom confided to me that she feels uncomfortable talking to my sister about her struggles, her changing relationship with my dad. She doesn't like to ask my sister for help, even though my sister lives just a few miles away and will help in every way that her own family and work commitments allow. My mom feels like she's burdening her. "I don't know why, but I prefer to talk to you." "I guess I don't feel as guilty talking to you", she said. "Please talk to me," I urged. "Let me support you in that way. It's the least I can do."

That conversation has helped us both to realize that my role has been to care for my mom as my dad's caregiver. She is able to ask for emotional support or listen to suggestions from me *because* I am not there, in the thick of it. My role as a long-distance daughter has become clearer. I can even accept its limits—at least for now.

Cape Breton Long Johns

(also known as "Fat Archies")

½ c shortening
½ c butter
1 c brown sugar
1 c molasses
1 egg (beaten)
3 tsp baking soda
¾ c boiling water

5 c flour
1 tsp cream of tartar
1 tsp salt
½ tsp cinnamon
½ tsp ginger
½ tsp cloves

Cream shortening, butter, and sugar until light and fluffy. Blend in molasses and egg. Continue to cream. Dissolve baking soda in boiling water and add to mixture. Sift together dry ingredients and fold into mixture. For drop cookies, drop by teaspoonful, spaced well apart onto a greased cookie sheet. For rolled cookies, chill mixture, roll out 1/4 inch thick and cut into desired shape. Bake at 375 degrees until lightly browned.

Driving conversations

By Brenda Sangster, Caregiver Support Coordinator, Capital District

I was fortunate when my 85-year old mother recognized on her own that it was time to give up her driver's license. After her cataract operation she had no desire to drive. In fact, my mother now enjoys being chauffeured, just like Miss Daisy. As a caregiver, one of the many difficult issues you may face is when and how to start the conversation about driver safety. Taking the keys away from a parent or spouse is not easy.

Age may not be the only reason why someone should stop driving, but for many people it is certainly an important factor. According to Statistics Canada, although "most seniors drive carefully, statistics show that people aged 70 or older have a higher accident rate per kilometre driven than any other age group except young male drivers, still the highest risk category."

Age in and of itself does not mean older people should necessarily give up their license, and many older people are excellent drivers. But with age, certain conditions may develop that do interfere with the ability to drive safely and well.

For many people, for example, problems with vision increase as they age. Older people may not see things as clearly as they once did, and they may find driving at night difficult. Cataracts, macular degeneration, and glaucoma are all age-related conditions that can affect how clearly we are able to see and, therefore, the ability to drive safely.

Of course driving safely and well not only requires good eyesight, but also dexterity, agility, and a certain level of physical strength. Conditions such as Alzheimer's, heart disease, and diabetes can result in physical limitations that will affect a person's driving abilities. If you notice a decline in a person's ability to do everyday tasks, it might be the time to see if these changes are also affecting their driving.

If you have concerns, ride with the person and observe his or her physical ability to control the vehicle. Simply observe without nagging or distraction. Are they staying within the lane? How do they handle turns? Do they pay attention to the speed limit? In trying to drive safely, do they perhaps drive too slowly? Do they have the ability to scan from left to right?

Later, have a candid talk with them. Discuss your concerns and see if they will volunteer to give up their license.

If you are concerned and they refuse to give up the keys, talk to their physician or eye specialist; they can write a medical report to the Department of Motor Vehicles. Depending on the information in the doctor's report, Motor Vehicles may suspend the license immediately or they might require further medical or road testing.

Keeping active and social are important. If your spouse or parent gives up their license, find other ways to make trips to see friends or to visit the library, barbershop, hairdresser, or grocery store. In many places there are taxis and public transportation, or friends and relatives can be asked to help with transportation. Don't let giving up a driver's license negatively impact the person's life.

Hoarding

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

Hoarding, in its extreme form, is not a result of being messy or careless with belongings. It is not evidence of being a bad housekeeper. Neither is it a form of collecting—collections are displayed in a place of honour or are carefully stored.

Hoarders feel a strong compulsion to acquire items that may be of little or no value. They may, for example, hoard clothing, paper, pets, or even garbage. Hoarders experience great distress at the thought of parting with these items. Often starting in childhood, hoarding rarely becomes evident before adulthood. We now know that such behaviour is likely to be a sign of an anxiety disorder, and it is often accompanied by other mental health issues.

What causes behaviour such as this that can be so upsetting both to the hoarder and to family members and friends? It is strongly suspected that there is a physiological basis for severe cases of hoarding. There seems, for example, to be a genetic component to this disorder. "Studies have found that the frontal lobe within the brain of someone who hoards tends to work differently … this region is crucial for weighing options and thinking rationally. As a result, their priorities are different from those of non-hoarders …"[1]

It is difficult to determine exactly how many people are pathological hoarders, as the negative reaction from others often drives the hoarder underground; fearing criticism, the hoarder denies other people entrance to the home. It is, however, estimated that hoarding affects approximately 2.5% of the population. To put this into perspective, 1% of the population experiences schizophrenia and 2.3% obsessive compulsive disorder (OCD).

Hoarding can damage relationships. The child of a hoarder, for example, may suffer embarrassment by the condition of the home and by being unable to invite friends over. The spouse or adult child of a hoarder may experience growing anxiety, fearing the harm that can come to the hoarder or others who live in the house.

Safety, understandably, is a huge concern. Hoarding can increase the risk of fires (from hoarded items covering electrical outlets or appliance cords, from heat ducts that cannot cool off, from careless smoking around flammable items), infestations of insects and rodents, blocking evacuation routes in case of emergency, mould and air quality issues, or, injury or death when mounds of material fall are all inherent dangers.

Forcibly cleaning out the home can be emotionally devastating to the hoarder and may, in fact, trigger accelerated acquiring. Blaming, shaming, or calling-out the hoarder has no demonstrable success. There are recommended treatments, however, including cognitive-behavioural therapy, medication, or a combination of both.

Family and friend caregivers can receive help in understanding this devastating disorder by contacting local mental health services or by accessing the following resources.

thecaregivernetwork.ca/event/help-family-member-hoarder

ementalhealth.ca/NovaScotia/Hoarding/index.php?m=article&ID=13330

psychcentral.com/lib/10-things-you-should-know-about-compulsive-hoarding

bridgewaterpolice.ca/files/hoarding/HoardingandFireSafety.pdf
(Photo credited to this link.)

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[1] webmd.com/mental-health/features/harmless-pack-rat-or-compulsive-hoarder

Persistence and planning are key for parents

By Jennifer Briand, Caregiver Support Coordinator, Western Region

Many of us can remember how challenging our school years were and how important it was to remain focused and organized. Imagine trying to be part of a school system when you are having difficulty with activities of daily living. Imagine how hard it would be to focus, when you can't focus or when you can't comprehend what is being said to you. Imagine trying to get to class if you have to wheel your way through your peers. Every day is a challenge for children with physical or cognitive disabilities, as they need to work so much harder just to get through the day.

Years ago when I worked in clinics and schools, parents often told me that their children would go to bed every night, right after dinner, as they were so exhausted from trying to concentrate and from the effort it took to function, from the minute they woke up until the bus brought them home later in the day.

I was often amazed and humbled by these parents. From the moment their child came into the world, their lives changed. They went from Plan A to Plan B in an instant. They became not only parents, but also caregivers. Many quickly learned a great deal about their child's diagnosis; they also learned practical skills and could advocate when needed—which was often. Parents learned what it is like to grieve for their child and the life they may never have—never have their own independence or children of their own. But parents also know tremendous joy, with each new accomplishment and connection with their child.

When you become your child's caregiver, it takes an enormous amount of energy and fortitude on your part everyday. It is also important to take care of yourself and seek out support wherever you can. Parents should pay attention to their own nutritional, physical, and emotional needs so they can recharge their batteries. Some of these parents have made their way to our caregiver support groups, and I'm so glad they are accessing extra support for themselves. It does take a village to raise a child…and to take care of their parents too.

I have asked some of these special caregivers what advice they would pass on to new parents. I wasn't surprised to hear very similar advice from each of them: They all said, "It is ok to dream new dreams for your child and to adjust your own goals". "You will realize how much strength you have when you are advocating for your child in a system that does not always cooperate." *"Be persistent, you know your child and their needs. And most of all plan for the future, as you will not always be there, in their future."* Advance care planning will help prepare for your child's financial and life needs.

For more information regarding advance care planning for caregivers contact, the Caregivers Nova Scotia office at 1.877.488.7390.

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.

Transitioning to long term care

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

One of the hardest decisions you as family or friend caregivers will have to make is whether your loved one needs to move to a 24-hour care facility.

This change can be an emotional rollercoaster, as you come to the realization that you are no longer able to give them the care they need. But still, you will inevitably wonder, "is this really the right decision?" You may have said "I will never put mom or dad in a nursing home", but the day may come that their health needs have become too complicated for you and other members of the family to handle.

Just remember one thing: you are not doing it "to them" but "for them".

When making the decision whether the time has come that your loved one now needs the level and degree of support that can only be provided in long term care, some of the things that should be considered are found on our website and include:

- **Changes in behaviour** - Are they more irritable than usual, or more angry, sad, or withdrawn? Maybe they're a little more confused and forgetting or repeating conversations or medications?
- **Safety concerns** - Are they starting to wander or are they falling more frequently? Are you concerned with them using the stove or has their driving become a concern? Have they lost weight due to poor eating habits?
- **Activities of daily living** - Is getting out of bed or just walking becoming a chore for them? Are they having problems preparing meals, bathing, and dressing? Is the home unkempt and cluttered?
- **Financial Concerns** - Are bills unopened and letters piling up? Are there thank-you notes from charities for recent donations?

As well as all of the above, perhaps they have developed health issues that are just too complicated for the family to handle and will need 24 hour monitoring. The family may not have the knowledge or ability to deal with these problems. And if someone has to stay with them, can the family just drop everything to come to their assistance?

Just remember when making the decision, include everyone in the conservation. Do your homework as to which facility would be the best for your loved one; you can tour the different facilities and see what each has to offer. Take into consideration your loved one's personality and what is most important to them, so they will enjoy being there.

Having worked in a LTC facility for close to 25 years, I can say from experience that I have seen good and bad transitions into care but, overall, the majority have been good. Often the quality of the relationship has actually improved for the family, as they can enjoy the visit, instead of worrying about all the caregiving duties that they were responsible to handle.

Also, as family members who care deeply about your loved one, you will have the peace of mind that they are getting the best care possible.

If you've 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.

Mindfulness

By Lynn Butler, Caregiver Support Coordinator, Capital District

One topic that comes up at support group meetings is the importance of mindfulness and of being more mindful. But, what exactly does it mean to be mindful and what is mindfulness?

Well, basically mindfulness means paying purposeful attention to the present moment, rather than worrying about the past or future. It involves acknowledging and accepting—without judgment, but rather a gentle curiosity—what you are feeling and thinking. When you are able to become more aware of what you are thinking, how you are feeling, and what is happening in your body, you give yourself the opportunity to change the way you react to any given situation. It has been proven that mindfulness can help reduce stress and its negative impact on your mental and physical health.

Here are a couple of ways you can try to be more mindful as you go about your day. When you wake up in the morning, instead of jumping up and starting your daily routine, take just a moment, relax, and lay there. How are you feeling? What emotions are present? Is your mind calm or are you already planning your day and what needs to de done? Try concentrating your attention on your breathing. Close your eyes. Take five mindful, slow breaths, focusing on each breath as it goes in and as it goes out.

At various points during your day and before you go to bed, stop and do the same thing. Think about how you are feeling, about what’s going on. Then focus your attention for a moment on your breath, your breathing. Take five mindful, slow, deliberate breaths.

Another opportunity to try being more mindful is when you go to eat or drink something. Most of us eat on the fly. We don’t take time to savor our food or appreciate the effort that went in to growing it or preparing it. At your next meal, before you dig in, stop, look at your food, savour the smell, then take a bite, chew, and swallow. Relish and appreciate your ability to eat and the food you are eating. Enjoy your food.

Every moment of your life will not be mindful. This is just not possible. Mindfulness takes time, practice, and patience, but the benefits are definitely worth the effort.

For more information on mindfulness and meditation you could contact Mental Health Services, a local yoga instructor, or access one of the following web links.

Mindfulness – The Superpower
youtube.com/watch?v=vzKryaN44ss

Just Breathe
youtube.com/watch?v=RVA2N6tX2cg&t=106s

Meditation for Beginners
youtube.com/watch?v=mtsdz_jhB7c

Guided Meditation with Sharon Salzburg
youtube.com/watch?v=YeeDo-c3lDI