# e Connection ommunity

# **Summer 2013**

Issue 27

# **Mastering the Balancing Act**

Carol Annett ~ CEO & President, VHA Home HealthCare

I love the two sides of summer. On one hand, Toronto, where I live, is full of activity from June to September. Festivals and tourists abound; patios are bustling with patrons; and children and adults play, bike, rollerblade and frolic in the parks around town. On the other hand, it is also a more peaceful time when most people embrace a slightly slower pace and take advantage of opportunities to put their feet up and relax from the hustle and bustle of the rest of the year.



I was reflecting on this duality and the words of Dr. Tiffany Chow who recently spoke at VHA's Heart of Home Care Awards in June. Dr. Chow is a renowned neuroscientist with Baycrest, who specializes in dementia and Alzheimer's – two conditions that are quite common among VHA clients. At the awards, Dr. Chow spoke about the two sides of caregiving. To a packed room of professional and personal caregivers, she explained the importance of not only attending to the needs of the person receiving care, but also taking – and making – quiet moments to attend to oneself.

The act of caregiving often demands 100% of the caregiver's capacities, and in many cases loving caregivers put their own needs on the backburner. "You're not going to do very well for yourself or for anyone else as a caregiver unless you feel 1) safe, 2) loved, 3) happy and 4) healthy. If you don't have all four of those going on, it's very hard to provide it to someone else," said Dr. Chow. While our Heart of Home Care awards celebrate those friend and family caregivers who go above and beyond, our selection committee also strives to recognize individuals who care for themselves as well.

Dr. Chow's message resonated strongly with everyone in the room, as she itemized ways to achieve that all-important balance. If you get a chance to read her book The Memory Clinic, I highly recommend it. It is an excellent analysis of Alzheimer's and dementia from a medical, personal and caregiver perspective.

Balance is also important at an organizational level. VHA has always focused on our clients and finding ways to provide the highest quality care that creates more independence for them. We encourage best practices across our services and our staff and service providers have taken this to heart. Our nurses, for example, recently completed their Annual Advanced Competencies/Best Practice Review, which ensures that everyone is aware of best practices and is providing high-quality nursing care to our clients. In the GTA, we partnered with George Brown College to use the school's equipment and lifelike models at their new waterfront campus. Nurses demonstrated how they deliver care to our clients and received feedback from supervisors and clinical champions.

On the lighter side of things, VHA's staff and service providers celebrated another year of accomplishments at staff appreciation events this spring. Amid the socializing we recognized our long-service staff and the winners of VHA's Barbara Blackstock-Cody awards for service excellence. This year's winners— Angelita Tare, Personal Support Worker, Jocelyn Lai, Physiotherapist, and Kevin Rice and John Xu of the IT Team—honour VHA's rich history, reputation for excellence and our commitment to providing clients with spectacular care.

I hope that as the summer winds down, you too have been able to find balance in your life and that you continue to take care of yourself as we enter the inevitable hectic 'fast forward' fall season ahead.



# **Celebrating the Heart of Home Care**



Now in its ninth year, VHA's Heart of Home Care award recognizes the extraordinary efforts of a friend or family member who goes above and beyond the call of duty to provide a loved one who is disabled, elderly, or chronically ill, with the support needed to live at home with independence.

This year we added a category to our previous two, and recognized the efforts of a *Caregiver to an Adult*, *Parent Caregiver of an Adult Child* – 18 + Years, and a *Parent Caregiver of a Child Under* 18 Years. Our intention was to choose one winner per category, however, the nominations we received this year were so inspiring and deserving of this special recognition that it was very difficult for our selection committee to choose only three. Ultimately, four nominees received the Heart of Home Care Awards for 2013.

This year's winners were Kelly Beatty of Oshawa, Jose Lino of Toronto, Jenni Ward of Keswick and Leomina Valderrama of Scarborough. "All of these winners truly embody the dedication, strength, compassion and courage of caregivers everywhere," notes President and CEO of VHA Home HealthCare, Carol Annett. "The job of a caregiver is a demanding one with lots of challenges, and it often isn't acknowledged by the outside world. The Heart of Home Care Award really is VHA's way of saying 'thank you' to these amazing caregivers and brings attention to the need for more caregiver support and relief."

### A Wife's Devotion to Her Husband

Kelly and David's love story began more than 40 years ago when they met at Ryerson University. Kelly worked in the office as the head secretary of the business department. One day a student named David came in waving a parking ticket and letting her know that under no circumstances was he going to pay it. A few minutes later David left the office having paid the ticket. You could say David met his match! A few weeks later, and completely by coincidence they found themselves on a double date and hit it off. This was the beginning of a long and loving marriage that resulted in three children.

About 21 years ago David and Kelly realized something was wrong when David had a couple of very bad falls while visiting their son Chip in England. Shortly after, David was diagnosed with Multiple Sclerosis (MS) at age 58. Tragically, a few years later, Chip was killed in a car accident while visiting his older brother in Thailand. "Six months after Chip's funeral David was bedridden. I really think it was because of the shock and loss of our son," says Kelly.



Kelly Beatty (centre), winner of the Caregiver to an Adult award, with her husband's VHA nurse (left) and her daughter (right) and granddaughters.

Kelly has always been in a caregiving role, running a daycare out of her home for 30 years. However, with David gradually becoming more physically disabled she stopped her home daycare business to be a full-time caregiver for him, managing all of David's personal and medical care needs. In 1999, Kelly was diagnosed with breast cancer. Amid the treatments and toll on her own body, she still managed to care for her husband the best that she could. For several years, Kelly was also involved with the MS Society and often blogged to share her story and learn from others in similar situations. "My mom just always smiled no matter what. She never had a breakdown, folded or complained. We would shake our heads, like 'how do you do it?'" notes Kelly's daughter Heather.

In 2012, during the Christmas holidays, David was sent to the hospital in very poor condition. The staff suggested that Kelly put David in a long-term care facility or learn how to care for him at home with a feeding tube. Kelly chose home. Unfortunately, in March of this year, David lost his battle with MS. Kelly is extremely thankful for the support she received through the Community Care Access Centre (CCAC) and for the fantastic help from their VHA nurse, Mary Beth Chamberland, who was with the pair for 15 years. "One of my duties was to teach and help Kelly, but I never really expected to learn as much as I have from her," says Mary Beth. "She had great rapport with all the home care staff. She was non-judgemental, caring and considerate, eager to learn, adaptable, funny and very loving towards her family and friends."

Kelly says she couldn't have done it for so long without all the help. But most of all she thanks her husband David for being such a great patient. "He was just the best person to look after and anybody would tell you that. He was a top dollar patient! I just loved caring for him," says Kelly.

### The Love Between a Father and Daughter Can Never Be Broken

Jose has been caring for his daughter Marta at home for more than 37 years. For many years, Jose and his wife worked together to care for their daughter who was born with Down Syndrome and Autism. The most



Jose Lino (right), winner of the Parent Caregiver of an Adult Child award, with his nephew.

difficult part of her health condition is the behavioural impact – Marta will often scratch, scream and spit.

Since his wife's passing more than six years ago, Jose has carried the lion's share of the caregiver workload. Jose lives alone with his daughter and although he has loving family members who help when they can, Jose takes on almost all of the

responsibilities of providing Marta with round-theclock care and supervision. This incredibly devoted father has put his life on hold to care for his daughter's personal and medical needs, including bathing, feeding, dressing, toileting, meal preparation, laundry and so much more.

Jose does get some relief and receives approximately eight hours of home care each week from the CCAC, and Marta is at a day program three days a week. Jose typically spends this little free time doing shopping, chores and running errands. As he gets older he is concerned for Marta's future since there is no one to care for her should anything happen to him.

The love this father has for his daughter is truly unconditional. "He is just a lovely man. I have never seen anyone care for their child the way Jose cares for Marta, especially not a father caring for a daughter," says Maureen Gludd, who nominated Jose for the award. "I've worked for VHA for 12 years and I have never seen anything like this. He takes such good care of his daughter," she adds.

### No Love Like a Mother's Love

On July 3, 2002, at just 33 weeks pregnant, Leomina Valderrama gave birth to her son Brendall, weighing in

at only 3lbs. Unfortunately, the premature baby was critically ill and spent his first four months of life in five different hospitals. Brendall was born with several respiratory problems that have left him non-mobile, non-verbal and requiring a gastrostomy tube (g-tube). "Even though he hadn't yet been diagnosed, I knew when I brought him home that I was caring for a special needs child," says Leomina. Brendall



Leomina Valderrama (right), winner of the Parent Caregiver of a Child Under 18 award, with her son Brendall's VHA nurse.

has had multiple seizures and has been diagnosed with cerebral palsy. Because of his many medical conditions Leomina is a stay-at-home mom providing her son with 24/7 care.

If the stress of raising two young children – one who has several health conditions – wasn't challenge enough, in 2004 and again in 2007, Leomina was diagnosed with breast cancer. "With all of these things happening in my life, I would ask myself, 'How can I do it?' I truly believe I kept going because of Brendall; he really makes me strong," says Leomina. During this time, Brendall was living at Sick Kids Hospital and she recalls going to Sunnybrook Hospital for her treatments and then trekking back to Sick Kids to be with him. Leomina is grateful to the CCAC for increasing her hours of support when she got sick and especially thankful to Janeth Valenciano, her VHA Home HealthCare nurse, for being a wonderful and wise support through the years. Initially the family lived in an apartment that barely accommodated the equipment that Brendell needs to survive. Fortunately and with a lot of advocacy efforts from Leomina, her family was able to get a Habitat for Humanity Home, which has made a huge difference in their lives. Leomina now volunteers as a spokesperson for Habitat for Humanity.

Despite many challenges, Leomina considers herself lucky to have such a wonderful son and cherishes the joy he brings to her life. She describes Brendall as an amazing gift from God. "Looking after a child like Brendall is a special gift. He is a beautiful child and I try my best every day to give him the quality of life he deserves," says Leomina.

Leomina is most proud of being the voice that her son doesn't have. She believes many caregivers can do what she does. "It's all about hope. Although there are many challenges and it isn't always easy, you will find the joy in caring for your loved one," says Leomina. "There is always a light at the end of the tunnel and the sun will always shine! It's okay to cry when you don't know what to do, and when you need help, ask for it. There will always be someone who can help you," she explains.

### A Champion for Her "Little Man"



Jenni Ward (left), winner of the Parent Caregiver of a Child Under 18 award, with her daughter.

Jenni Ward is a full-time mom and caregiver to her nine-year-old son Blake. When Jenni was pregnant with Blake, an ultrasound revealed that he had an enlarged heart. He was diagnosed with a heart condition called hypoplastic left heart syndrome (HLHS), in which the left side of his heart is underdeveloped.

For the past nine years,

Jenni has been Blake's rock and supporter, advocating for what she knows is best for him. "Jenni never raises her voice. Although sometimes stern, she is always calm and always [speaks] with love," says VHA Occupational Therapist Helen Dixon, who nominated Jenni for this award.

An aspect of Blake's condition is hyperactivity, which can be a challenge. When he was about five years old, Jenni suspected Blake had some hearing issues. It took her several years to convince health professionals of this, but he was eventually diagnosed with severeto-profound hearing loss in both ears. It is suspected that his behavioural issues were the result of his frustration with not being able to communicate and hear. After much hard work and advocacy on Jenni's part, Blake was taught sign language and now is able to communicate.

Day-to-day care for Blake is intensive and Jenni has taken on most of it on her own, although she has always had home care services. Currently Blake is on 36 medications that Jenni administers from 7:00 a.m. until 11:00 p.m. "He is my little man," Jenni says. "I listen to his heart, I change his g-tube and can do almost everything the nurses can do."

This year has been the most difficult for Blake and his family as his condition progressively worsens. When Jenni was recently given the news that things were not looking good for Blake, instead of shutting off and grieving, she decided to have a party to celebrate Blake's life. She invited all of his friends, family, therapists and caregivers so those close to Blake would remember him as a vibrant child full of life.

"Anybody that meets Jenni is lucky to have had the opportunity. She encourages those around her to live and value each and every day like she does," says Helen. Blake now requires oxygen and has to be monitored closely. The focus of his care is on making him as comfortable as possible. Blake is not like a typical child because there are still communication barriers and sometimes he won't say he is in pain until Jenni asks him.

"I always try to stay positive and keep a smile on my face. People tell me I have a 'heart of a lion," Jenni explains. As she watches Blake's health decline, Jenni is as heartbroken as any mother would be but she says "these have been the best nine years of my life."

Each of these caregivers are extraordinary people who have only ever viewed what they do as ordinary. They all say that caring for the people they love is what's in their heart. Our winners represent the incredible dedication and love that is required of a caregiver and we hope that this award will continue to shed light on the enormous role they play within their families and in our society.



# **Eye on Quality**

# **Our Improvement Journey Continues...**

Our Vision and Mission is to provide each client with a spectacular experience with VHA's services. That is what we strive for at VHA with every client, every time. The client's experience is measured in many ways, such as client surveys and monitoring of complaints and compliments. We fortunately have performance results that are robust and longitudinal, monitored over a number of years. This information is vitally important in assessing how well we're doing and directing our improvement efforts.

While much work remains to be done —we are far from perfect— recent evidence shows significant improvements in our clients' experience. We can't always pinpoint the exact reason for the improvements, but we do know that our combined efforts are making a difference. Complaints are on the decline and positive client experience survey results are on the rise. Research, best practice information and common sense guide our improvement work and tell us what we need to continue doing. Things like:

Upgrading staff education in Client Centred Care. We recently revised and refreshed VHA's Client Centred Care course in conjunction with our work towards our RNAO Best Practice Spotlight Organization candidacy. The new course began this summer with our Personal Support Worker teams and in 2014 will be rolled out to the Nursing and Rehabilitation disciplines.

Tools and processes to support staff to provide excellent care and manage the challenges they face. *Changing the Conversation* training and ethics educational sessions have given staff simple, userfriendly tools to guide them in client-centred and ethical practice.

**Orientation and Peer Preceptor** programs were enhanced this year.

**Bringing in the client voice** at all levels of VHA's organization and programs is a strategic direction this year. Client engagement work at VHA is guided by research literature, as well as the experience of other health care organizations that have kindly provided excellent advice and tips as we begin our client voice initiatives.

As we embark on this effort, we take the words of Hugh MacLeod, CEO Canadian Patient Safety Institute (CPSI), and Carol Kushner, Co-Chair of CPSI's Patient For Patient Safety Canada program, to heart:

"One way to speed up the transformation of your organization on the path to patient-centred care is to involve patients (current and former) and their family members on the teams responsible for planning, implementing and evaluating safety and quality initiatives. ... Bottom line: there is simply no better way to ensure that the patient perspective is reflected in your work than to include them, listen to their input and respect their unique contributions." (MacLeod and Kushner, 2013)

<u>Reference:</u> MacLeod, H. and Kushner, C. **The Patient Voice A** Value Game Changer. Longwoods.ca, Essays March 2013.

# **Pursuing Nursing Excellence**

Congratulations to six VHA nurses who recently earned the specialty certification of Community Health Nurse (CCHN(C)) from the Canadian Nurses Association: Catherine Newman, Fely Palmares, Juniefer Villanueva, Marjorie Kebbe, Olive Mabborang, and Pamela Stuckless. The CCHN(C) designation indicates that a nurse has met high standards set out by the Association for clinical experience, proficiency and theoretical knowledge in the unique practice of community health nursing. Since 2006, only 782 nurses across Canada have earned this challenging and voluntary specialty designation. These nurses' achievement represents a commitment to leading-edge practice and will undoubtedly enhance VHA's client care and the application of best practice solutions at the bedside.







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30 Soudan Avenue, Suite 600, Toronto, ON M4S 1V6



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- Speech-Language Pathologists
- Client Service Coordinators/Supervisors

VHA Home HealthCare is a member agency of United Way Toronto and a contracted provider with Toronto Central, Central, Central East, Central West, South West, Mississauga Halton, Champlain, and Erie St. Clair CCACs, the City of Toronto's Homemakers and Nurses Services program and the Regional Municipality of Durham.

# We welcome your support!

### Membership

VHA welcomes new associate members and encourages people in the community to get involved with VHA. Our membership fee of \$25 can be waived in special circumstances. Please contact Patricia Triantafilou at 416.489.2500 or patricia@vha.ca.

### Donation

Charitable donations to VHA Home HealthCare make a meaningful difference in the lives of people in need. Donations are welcome online, by mail, phone or in person. Our sincerest thanks for your generosity.

**Comments or Suggestions?** Contact the interim editor of Community Care Connection **Jo-Anne Liburd** : 416.489.2500 x4344 or 1.888.314.6622 email: jliburd@vha.ca

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