

### EXCELERATOR

The latest developments within our walls and across the communities we serve



#### ADDING UP THE BILL FOR UNPAID CAREGIVERS

A research initiative explores the costs to family caregivers

#### BIOMETRICS TO REDUCE PSW INJURIES

work-related injuries for VHA's personal support workers

#### ASPIRING TEACHER VOLUNTEERS AT VHA

VHA's Child and Family Volunteer
Program was everything she wanted
from an internship and more

# ADDING UP THE BILL for Unpaid Caregivers

When Muriel was diagnosed with dementia, her daughters shared the responsibility of caring for her as long as they could. They purchased personal support services, took time off work, set up a bed on the main floor of each sister's house and eventually paid for long-term care when home care became unmanageable. It's a common scenario.

"We know that in Canada, rates of dementia are on the rise. In Ontario we see a number of dependent elderly with dementia living at home now," says Husayn Marani, one of three Junior Researcher Development participants brought on to work with VHA Home HealthCare in 2018. A third-year doctoral student at the University of Toronto's Institute of Health Policy, Management and Evaluation, Husayn is researching the costs for family caregivers looking after a loved one with dementia at home.

Ontario's Aging at Home strategy acknowledges this type of care has many benefits and encourages it, notes Husayn. "It obviously helps dependent elderly, including those with cognitive impairment, age with dignity within their home, [and] there are economic

benefits by shifting the responsibility from the community to the individual. However, we're starting to see that the shift in cost is being imposed on family caregivers themselves," he says.

Anecdotally, we know family caregivers cover numerous out-of-pocket costs for things such as home upgrades, transportation, respite care and in-home care providers, and many of these costs do not have available subsidies. There are also opportunity costs from not pursuing employment or advancement in order to provide unpaid care. There is little research available about the extent of these costs, how caregivers experience them and how well they feel protected from financial risk by government supports.

"We also don't know if caregivers for people with cognitive impairment experience these costs differently than caregivers for people with other conditions. I hope my research might unearth these things," says Husayn. "These costs may be contributing to issues like financial burnout that compromise the quality of care that caregivers can provide."

Working with VHA has given Husayn access to important research connections to support his project development. The first part of the study is a qualitative analysis of the costs that family caregivers perceive they have. Husayn is working with VHA to connect with a diverse group of caregivers from across Ontario who are interested in participating. The second part of the research is a quantitative analysis of available data, such as government information on home care costs, to see if these align with the qualitative findings. "If they don't correspond, it calls into question whether the financial supports available from the government accurately capture or protect against the true costs that caregivers are experiencing out of pocket," says Husayn.

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In shaping his research project, Husayn has already spoken to many caregivers, which had an unexpected impact on his approach. "When I started this research, I spoke of these costs as a burden to caregivers. But many caregivers see these costs not as burdens but as responsibilities—something that they do because they are caring for their loved one who has dementia," he explains. "In fact, as caregivers for my mom who has MS, my family does not view the costs for home upgrades or the costs for her care as burdens. They are something that we do out of love and responsibility and caring. I think that difference will shine through as I conduct my research. It has informed the way I have developed my interview guide."

Husayn will defend his proposal later this year and is excited to begin the qualitative stage of interviews.



Husayn Marani, a 2018 VHA Junior Researcher Development participant, is working with VHA to research the costs for family caregivers who are caring for loved ones with dementia at home.

"Family caregivers now face a huge responsibility. They are saving the government a significant amount of money through their unpaid work and I think there is a responsibility on the government to protect family caregivers from these financial risks. I hope my findings will inform strategies and targeted interventions for caregivers and will help demonstrate the critical role unpaid caregivers are playing in dementia care."

To watch a video about Husayn's research visit: <a href="https://bit.ly/2OCLizS">https://bit.ly/2OCLizS</a>.



## Aspiring Teacher Gains Volunteer Experience with VHA

Brooke Lothian has always had a way with kids. The third of four children, she had a close bond with her baby brother and was always mentoring younger students in her dance class. "They would gravitate towards me. I was a role model, I guess," she says modestly. "I think it was my dance teacher's husband who suggested, 'Brooke should teach! She's really good at it.' I didn't even think about it and just said 'Yeah!' So at 15, I started teaching dance."

Today, Brooke is in her second year of Ryerson's Early Childhood Studies program, which is how she found another way put her skills with kids to use—as a VHA Child and Family Support volunteer. VHA was one of the internship options her professor presented, and

when Brooke
researched VHA and
the program, "it was
everything that I
wanted out of my
internship and
volunteering," she
says. "And I got even
more than I wanted. It
was awesome."

The Child and Family Support program matches volunteers with families that are



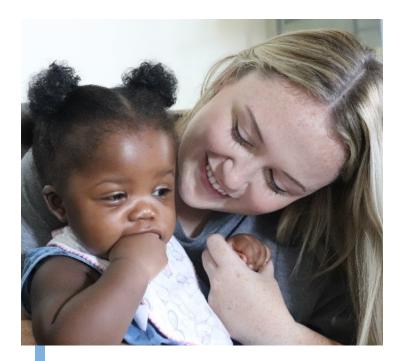
Brooke has been a volunteer with VHA since May 2019.

experiencing multiple stresses and isolation. The volunteers visit the families and act as a resource to make positive changes in their lives. Volunteers interact with their young children (less than five years old) and help the families discover and connect with social supports in their community.

Since Brooke began volunteering with the program in May, she has worked with eight families. Often her role is simply being there for the family, helping the parents navigate situations, connecting them to resources and being a sounding board or solving problems. "With Brooke, I was able to catch up on reading and research, because I want to go back to school and work parttime," says Charlene, a VHA Child and Family Support client. "One of my goals was to start the process of driving. I was able to study for my G1 and I went for my test and passed, thanks to Brooke. I'll always remember Brooke for that!" she adds.

Seeing the impact her support brings families has been particularly rewarding for Brooke. "One of my clients was feeling very overwhelmed. She has four young kids and had just broke her foot. She's also an immigrant and doesn't know much English." The client had a mixup with her taxes but struggled to address it because of the language barrier. Brooke was able to be a go-between with the CRA and help resolve the misunderstanding. "It made me feel really good, knowing that I helped with a little thing that I could do—being a communicator. My client was so thankful that the problem was resolved and she didn't have to worry about it anymore. She could focus on something else, like her children or self-care."

Brooke also goes on outings with the families. "A lot of my families just stay at home because they are comfortable there or it feels like too much to take all of their children out alone. Just being able to go to the library or the park and get some fresh air or change up their environment is possible now. And seeing their children interact with other children or with nature is really rewarding for them. They really appreciate it."



Brooke gives baby Abigail cuddles during a visit while her mom Charlene takes time to get things done—like studying for her G1 driving test.

Charlene echoes this sentiment. "I really appreciate Brooke's time, effort and care. I could I see from the very beginning that her heart is in what she's doing. She will go far."

Being a Child and Family Support volunteer has Brooke more excited than ever for her future as a teacher and the variety of encounters she will have. "Every family is unique – seeing how they work really opens my eyes. I just want to keep going. I've made so many good relationships with these families and knowing that I made that difference is amazing."

Amazing is a word that comes up often when Brooke talks about volunteering with VHA. "This is probably one of the best experiences of my life. I would definitely recommend volunteering at VHA for everyone. I've learned so much. It is so rewarding. I'm so glad I did it."

To hear more about Brooke's experience, please watch a video here: <a href="https://bit.ly/2MtC1HV">https://bit.ly/2MtC1HV</a>. To find out more about VHA's Child and Family Support volunteer program, visit <a href="https://www.vha.ca/volunteer">www.vha.ca/volunteer</a>.

## VHA Announces Junior Researcher Development Award Winners for 2019

VHA Home HealthCare developed the Junior Researcher Development Awards to offer mentorship and funding opportunities for young researchers who have an interest in studying and advancing evidence in home care. This year we received a lot of strong applications, and are pleased to announce our three winners.



Alla Yakerson holds a Master of Science degree from the University of Toronto in Physical Therapy. She is currently a PhD candidate and teaching assistant at the School of Health Management at York University. Alla's research interests include access to health care services and pain management, and she is particularly interested in fair access to home care services in Ontario. As a practicing physiotherapist, Alla focuses on scientifically proven methods and research that make treatment more effective.

Alla's research at VHA will focus on improving experiences for unpaid caregivers by developing an educational tool to train on proper safety techniques while providing care.

Kristina Smith is in her fourth year of doctoral studies in the Faculty of Kinesiology and Physical Education at the University of Toronto, where she is completing a joint degree with the Joint Centre for Bioethics. Kristina's research focuses include the depth of human pain, suffering, illness, paediatric care, bioethics and narrative ethnography.

At VHA Kristina will explore the experience of waiting for a transplant at home as a form of suffering for paediatric transplant candidates. Her research will inform how homecare resources and policies can improve and ensure that families receive safe and effective care. This research is aligned with VHA's research focus on children with complex medical needs.



Todd Tran is an occupational therapist working at Women's College Hospital. He is pursuing doctoral studies in the Faculty of Health Sciences, School of Rehabilitation Therapy in the Aging and Health Stream at Queen's University.

Todd's research work with VHA will study the impact of mindfulness on cognitive impairment in older adults. Todd aims to demonstrate that mindfulness may be an effective strategy for adults in community dwellings to reduce psychosocial concerns, promote satisfaction in performance and support aging.



## From a very young age, Joyce Umoren dreamed of becoming a nurse. "What inspired me was the incredible attention and care I received from nurses when I was young," she explains. She told her mother at age 6, "When I grow up I would like to be a nurse". When the time was right, Joyce's mother was supportive of her dreams, and guided her through the path of fulfilling her goals. Joyce trained as a nurse internationally. When she arrived in Canada in 2011, she needed to renew her nursing certification, so she started working for VHA as a Personal Support Worker (PSW) and studied part-

"I spent my spare time and my evenings in the library reading books and catching up on my studies," she shares, "and during the day I would see my clients." Joyce used VHA's Work\$mart program to assist with all of her studies. Work\$mart is a VHA benefit that supports staff in their professional development by providing financial assistance for educational programs. "The Work\$mart program and the financial assistance it provides have been really helpful for me."

time for her certification.

At VHA, Joyce's journey continued to unfold. She passed her nursing exam and began working as a visiting nurse. Joyce then decided to apply for the position of Care Team Supervisor. "I was interested in the Supervisor position because I really like working with PSWs and I have been in their shoes," Joyce explains. "I can give them insight on what works and what doesn't."

Joyce's advice to the PSWs she works with is to

## Following her Path—with Joyce Umoren

assess the client at each visit, to respect their needs, and to understand their disease process. She notes, "It is important to know the client's family and what the client expects from their care provider." Joyce encourages her PSWs to fill out a client preference form. "When the regular PSW is not available, and a different PSW is filling in, they will be able to read the client's preferences and immediately know their needs," explains Joyce.

"For example, they will know that Mrs. Smith likes to have a cup of tea after her shower. Imagine how happy Mrs. Smith will be when her new PSW offers her a cup of tea when she comes out of the shower." Another tip Joyce suggests is spending the last few minutes of the visit asking the client, "Is there anything else I can do for you?" It could be little things such as bringing the remote control to the client or opening up the curtains. "A little gesture can mean a lot to the client!" adds Joyce.

Joyce's journey at VHA is ongoing and she continues to learn and work to achieve more in her career. Here are three tips from Joyce for anyone looking to advance in their career:

- 1. Be passionate about your choice of career.
- Set a goal and be determined to pursue it. Quitting should not be an option!
- 3. Take care of your health, stay focused and motivated.

To learn more about Joyce's story, watch our video at: https://bit.ly/2p5sBdF.

## BIOMETRIC RESEARCH AIMS TO REDUCE PERSONAL SUPPORT WORKER INJURIES

Personal support work is a physically demanding job. Repeated bending, lifting and stretching are all part of a day's work and, in addition to the potential for sudden acute injuries, "There are cumulative injuries that can happen," says Emily King, VHA's new Manager of Research Operations, who is also a postdoctoral fellow in Kinesiology at the University of Waterloo. "Tiny bits of damage—not really noticeable externally—accumulate over time and weaken the back, for example, leading to chronic pain."

Inertial Measurement Units, which track personal support worker body motion.



Emily is leading a new VHA-University of Waterloo collaborative research project aimed at reducing work-related Personal Support Worker (PSW) injuries. "PSWs get hurt a lot. Back pain is very common for them. The environments PSWs work in aren't set up for caregiving—they are people's homes—which can make it hard to provide care sometimes," Emily explains. The fact that this care is being provided in private homes also makes it more challenging to reduce injuries. "Other care providers are typically not around, so often no one will notice if a PSW moves their body in a damaging way. The goal of this research is to try to capture the movements the PSW's body is making as they provide regular care."

The study has been designed with privacy in mind.

There are no cameras in the client's home and no
personal health information is collected. "Our focus is
solely on PSW movement," says Emily.

The study uses movement sensors called Inertial Measurement Units that are attached to the PSW's arms, upper and lower back, thighs and lower legs to track the body's motion. Each sensor tracks two modes of data: how fast it is moving in each direction and the acceleration.

Emily arrived at the placement array for the sensors in collaboration with VHA PSWs. "I was chosen as a PSW advisor for Emily," says Latha Jaya, a VHA PSW who has been supporting Emily's work. "Emily used the sensors on me to find out if they fit my body properly and whether I'm able to deliver proper care for the clients with the sensors on. My feedback is helping her to improve the project."

#### RESEARCH IN ACTION

PSWs who choose to participate in the research meet Emily at an off-site location near a client's home prior to a care visit. After completing surveys about how they are feeling that day and a bit about their personal background, PSWs are fitted with the sensors and conduct a brief set of movement exercises to ensure comfort, to orient the sensors, and to synchronize the sensor data before leaving to care for the client.

After providing care, the PSW returns to Emily. "We process the data from the sensors and we have a little stick figure that shows how the PSW's body was moving through the visit. The PSW will look through what the stick figure is doing over time and help us identify what activities they were doing at that point in the visit, such as, 'Oh yes, that's when I was helping them to get out of bed', or 'that's when we were getting the client dressed.' If we can estimate the postures of the PSWs, then we can work out whether they are in postures that have been linked to musculoskeletal injuries," explains Emily.

This phase of the research comes after many steps to develop the research protocol. The study went through a thorough research ethics process to ensure it balanced risks and benefits appropriately. Emily then focused on making sure the sensor system worked properly. "We've been running a validation study in a lab at the University of Waterloo and things are looking good, which leads to the next exciting phase: taking this into the home," she adds.

This research has the potential to answer numerous questions about how PSWs are getting injured.

"We believe we have set up a very effective, long-term protocol. There is so much variation in client spaces,



Dr. Emily King and her personal support worker advisor Latha Jaya.

client conditions, how PSWs approach providing care... so to understand it all we need to collect a lot of data." The research might shed light on such unknowns as which client characteristics are likely to mean that providing care carries a greater risk for the PSW. Or how much variation there is in providing care to the same client over different days or by different caregivers.

"From [the data] we may be able to work out better ways to train people so they can provide excellent care in a way that is safer for them. Such as, are there ways of bathing people that are riskier to a caregiver's body?" says Emily.

VHA and Emily share the same motivation for pursuing this research: "PSWs are trained, valuable, and caring, and they have a lot of special skills they bring to the job. When a PSW is injured, we lose all of that experience and ability, which is incredibly sad. It affects their ability to make a living and their quality of life. We want to prevent those injuries to allow them to continue to do well and to be able to continue to provide care to the clients we know they care so much about," she says.

To learn more about Emily's research and how we are working to reduce PSW injuries, watch our video at: <a href="https://bit.ly/2ME1AHx">https://bit.ly/2ME1AHx</a>. This project has been funded by CRE-MSD, MITACS Accelerate, a CIHR Fellowship and VHA's Ideas2Innovations.



## MAKING A DIFFERENCE MEET VHA CLIENT PARTNER ZINTA ERDMANIS

Zinta Erdmanis was introduced to VHA's caregiving services in 2016, when her husband became ill and required palliative care. Now Zinta is one of VHA's Palliative Care Steering Committee members and a committed client partner. We sat down with Zinta to chat about her life, her experience with VHA, and the importance of being involved as a client partner.

#### How did you become involved with VHA?

In 2016, my husband was diagnosed with ALS and almost immediately became a palliative patient. My husband didn't want to be hospitalized, he wanted to live out his life at home. The Local Health Integration Network (LHIN) referred us to VHA, and he began receiving homecare, nursing and other services. After my husband passed away, VHA asked me if I would be interested in becoming a part of the palliative care steering committee. I was quite honoured, because I wanted to help others in the same position as I was.

#### Can you share some projects that you have worked on?

One of the more important projects that I was involved with was the development of the palliative care section on VHA's website. These pages provide information on palliative care, links to different disease websites, financial assistance information,

self-care resources and so much more. I'm very proud to have worked on this, because when I was a caregiver, I didn't have a lot of time for myself, and I didn't have time to look for information. Being able to provide caregivers information that's easy to source saves them a lot of stress, grief and time. The information on VHA's website is now being developed into a brochure and will be provided to palliative caregivers at home.

#### How has your experience been with VHA in general?

It's been good! The palliative steering committee work is something I very strongly believe in. It is such a horrible time for caregivers and their family members, and we are trying to make it as easy as possible for them. As client partners and caregivers, you want things to move quickly, and I am pleased that at VHA the projects have been moving quite quickly. I'm very

proud of VHA and their commitment to palliative care. It's an important initiative because as the population ages, there are going to be more and more people at home looking for end-of-life care.

When my husband was ill, it was a very lonely experience, even though I had my family and friends around. One day your life is perfectly normal, the next day you're thrown into a terminal illness, and your world is turned upside down. You have to learn very quickly where you can go, what your resources are, where you can find help—and that's not always easily available. I feel that I am helping others through my involvement with the palliative steering committee and being a client partner. The programs and the materials that we're developing are helping people who are in a similar situation, and I'm very proud of that.

#### Why do you think it is important for clients to be involved in making decisions?

I think it's a great opportunity for both VHA and their clients to be involved in decision making processes, because we each learn about the other's perspective. Until you've walked in someone else's shoes, you won't know what they're going through. I think VHA learns a lot about the complexities of palliative care and end-of-life situations from clients, and it brings a lot of compassion to VHA and their care providers. And clients learn a lot from VHA—they learn about the services that are available and they develop very strong relationships with the caregivers. During my husband's illness, our home care providers were amazing. They stayed in touch after my husband's passing and I felt like they became part of the family. There are so many compassionate people working at VHA!

#### What would you tell someone who is interested in becoming a client partner?

I personally found it very rewarding and stimulating, and I met a lot of new people. I think a lot of people who face death want to do something, but they may not be able to make that commitment to VHA in becoming a partner. I'm afraid that when my time on the palliative steering committee comes to an end, I will be at a bit of a loss and will need to find something else to do at VHA. In the end, becoming a client partner is worthwhile and very rewarding!

Please watch a video with Zinta to learn more about her story here: <a href="https://bit.ly/2M6Rw9P">https://bit.ly/2M6Rw9P</a>. To learn more about being a client partner with VHA, please contact ClientVoice@vha.ca.

#### **VHA NEWS**

The Registered Nurses
Association of Ontario
(RNAO) has renewed VHA's
status as a Best Practice
Spotlight Organization (BPSO)
for a two-year term to 2021.

The BPSO designation recognizes VHA's continued support to nursing and interprofessional teams to build capacity, maximize clinical excellence through best practices, and evaluate outcomes.



#### Congratulations to two members of VHA's leadership team who have recently received Master's degrees!

- Dr. Sandra McKay (left)
   completed her Master of Business
   Administration (MBA) degree
- Pam Stoikopoulos (right)
   completed her Master of
   Management Innovation &
   Entrepreneurship (MMIE) degree



VHA is proud to
work with a number of
partner organizations,
primary care providers,
clients and caregivers in
developing Ontario
Health Teams (OHTs)



We are involved in 8 (of 31) OHTs submitting a Full Application



VHA is an anchor/lead partner in 5 of these applications



We are a collaborative/supporting partner in 3 others



We are also a partner in 1 'Innovative' OHT model (Connected Kids) and 1 'OHT in Development'

We look forward to joining our partners in other OHTs where we provide service to build better care experiences for clients, families and care providers.

*Excelerator* is a VHA Home HealthCare newsletter sharing the latest developments from within our walls and across the communities we serve.

If you have comments about *Excelerator*, or would prefer to receive this news electronically, please contact our Senior Communications & PR Manager Tracey Turriff at tturriff@vha.ca or 416-280-8426.











Note: VHA Home HealthCare is not affiliated with or related to VHA Health & Home Support, also known as VHA Ottawa.

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