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Caring for the Caregiver How to cope when you end up in an unexpected role

ike so many, Barb Hopkins found herself as the primary caregiver for her mother. It's a role she is happy to fill, but one that was somewhat unexpected. "The time required to care for a parent or spouse grows slowly over time," she says. "Then one day you realize how much time and energy you are spending... and wondering what happened to your free time!"

As a former financial advisor and current board member of Family Caregivers of BC (FCBC), Barb understands the subject-- and the issues around it-- from every perspective. The list of tasks a caregiver undertakes varies from person to person, but includes advocating on behalf of a loved one, transportation, help with medication, personal care and financial assistance.

Hopkins says North American culture is not one which prioritizes caring for our elders, so the time and resource requirements to do so are not built into our lives. On top of that, many seniors are living longer than expected and, because of that, don't have the money to pay for care which forces family members into that role. As a result, many are emotionally and financially unprepared for caregiving. With an aging population, more and more people are finding themselves sandwiched between careers and caring for a loved one.

Caregiver call volumes at Family Caregivers of BC provide evidence of the growing need. Each year, they serve an increasing number of caregivers with a 36% increase in the past year alone. Education and Engagement Lead Janet McLean says their main role is to help caregivers understand the trajectory of the caregiving role and how caregivers can support their care recipient without jeopardizing their own health and wellbeing. One of the challenges she says is many caregivers don't reach out for help until there is a crisis-- on average about four years after they begin caregiving.

"All the evidence shows that the earlier a caregiver understands their role and reaches out for support, the longer they can manage without burning out. That benefits them, the care recipient, and ultimately the whole health care system as pressure for acute and facility based care services is reduced," McLean says.

Once a caregiver gives him or herself permission to ask for help, they're often surprised at the number of resources available -- many of them free and online or by phone. Family Caregivers of BC's Support Line is staffed with professionals who can help develop an action plan and point them in the direction of appropriate resources.

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Preparing for an Aging Community



Things to consider as baby boomers require more healthcare services hen you look at the growth on the South Island over the past two decades, the Western Communities is ground zero. In fact, according to Statistics Canada it grew 20.9% between 2011 and 2016. While many services and amenities are growing with that population, a key requirement is not: medical care. The Western Communities have the lowest percentage of people who are "attached" to a physician (73.8%) on the island.

That statistic comes as no surprise to Dr. Cheryl Cuddeford. When she started her practice on the Westshore ten years ago she specifically took on patients aged 70+. She regularly gets calls from nursing homes and specialty care facilities to take on more patients, but she simply can't. "Most of my patients have three to five medical conditions, and at least 70% of my patients are on at least five drugs. I love my work and the relationships I build with my patients, but an aging patient requires more visits for more complex issues. I simply can't provide the service I want with a larger practice."

And the need on the Westshore is only expected to grow. The population is expected to continue to dramatically increase. Exacerbating the situation is the fact that many older patients move to the area because it has the most affordable housing. Planning consultant with Island Health, Erdem Yazganoglu agrees there is a possible gap between expected population growth and the possible services growth.

"The challenge is to catch up services to the population growth"

Erdem Yazganoglu

The challenge is to catch up services to the population growth," says Yazganoglu. "This is probably not feasible only with increasing the service quantity-- we need to find innovative ways to deliver services as well."

Most specialty services, which is the care more seniors need, is provided at the Royal Jubilee Hospital-- renal, cardiac, joint specialists. If the services can't be moved, better transportation is needed to get the patients to their doctors. If care is too awkward to get to, it's care denied.

Watching families navigate the same issues repeatedly, Dr. Cuddeford has advice for anyone who will need to help a parent or loved one through medical services as they age:

Plan ahead as best as possible:

Before moving to a new area, research medical services and specialty care for your loved one's health issues. Consider how he/she will get to various appointments.

Be a vocal advocate:

Sometimes seniors can be afraid to ask for help. Understand their challenges and help them find solutions. Don't be afraid to ask questions.

While there is no immediate fix for the challenges in the Western Communities, the South Island Division and Island Health are working hard to create Primary Care Networks. By bringing together communities, allied care providers, and Family Practitioners, the hope is that all residents, including seniors, will soon be able to access primary care more easily and closer to home.



Efforts to improve patient outcomes for First Nations patients leaving care

A s the former Health Director for the Tseycum First Nation, Jennifer Jones was used to watching band members receive hospital care, receive no follow-up, and then find themselves back in the emergency room with the same medical problems. So, in late 2015 when an idea took shape on how to improve care for First Nations patients between offices and communities after they were discharged from hospital, she was happy to take part.

From the hospital's perspective, the problem was well-defined. "Some First Nations patients have family physicians, others do not, and there is very little disclosure from patients about what kind of follow-up they'll receive once they're discharged from hospital," says Dr. Ambrose Marsh, former Chief of Staff at the Saanich Peninsula Hospital.

The root of that problem, according to Jones is often the patient's past. "Someone with residential care trauma often says 'yes' to a doctor asking them questions, because that is how they've been taught to respond. In reality, they are confused about the next steps of care or how they'll access it. That interaction of miscommunication often means the care cycle just continues, rather than finding a patient seeing results," she says.

The discharge project began in earnest in August 2016 and was funded by the Shared Care Committee. As the project got underway, Michelle Ham with the Transitions in Care (TiC) initiative at the South Island Division of Family Practice was able to understand the scope of the problem and identify the barriers to care. "We knew one of the biggest challenges we needed to address is the lack of trust and communication between clients and healthcare providers."

But building trust isn't an overnight project. Ham started by engaging with First Nations leadership like Jennifer Jones and understanding their stories and the current cultural safety being offered through the hospitals. Based on information gathered in those meetings, the TiC project held workshops to better understand the challenges that patients were facing when they returned to their communities.

The second part of the project was to expand cultural sensitivity within the hospital, which was accomplished by holding educational seminars. Physicians admitted they struggle with who to contact after a patient is discharged, and understand how that communication-- or lack thereof-- could impact a patient's long term care. It takes very diligent work for a patient to acknowledge that they're a member of a First Nations community, and for the physician to get permission to get documents back to a specific person.

"We kept facing the same challenge-- each patient and each community has different resources. It's not as simple as implementing a plan. Each plan has to be catered to each individual patient's circumstance," says Ham.

This project became a perfect example of where the solutions work well on paper, without unique circumstances to take into consideration. However, in reality, there were too many variables for each individual case to make a viable long term plan that doctors and patients could embrace. As a result, the change over the past two years has been minimal, although the lessons plentiful.

But progress could still be on the horizon. The Journey Home Project, which began just after the Discharge Project at Saanich Peninsula Hospital, helped doctors and patients better understand palliative care from a First Nations perspective and provide care that meets the needs of patients. That project saw great success and the ways in which it succeeded can provide a template for how to move the discharge project forward in the future.

"While the goal of the discharge project is still good, I'm not sure we had the right approach when we started," says Dr. Marsh. "Through trial and error I feel like we're in an excellent place to build on the success of the Journey Home Project to build better relationships and provide better care to our First Nations patients."

Jennifer Jones is also optimistic. She says some of the changes have stuck and more patients are receiving follow-up care. "They are learning to self-identify when they're admitted. Doctors are slowly understanding how important that is and some are altering their medical instructions for follow-up care. When both sides see that return visits to the hospital are decreasing, everyone will be more eager to continue the work."



Mike spent the first two decades of his career in Winnipeg, Manitoba and Northwestern Ontario and currently works at Bayside Medical Centre in Brentwood Bay. Originally from Southern Ontario, Mike did his medical training at schools in Canada, Jamaica, and New Zealand. Mike values community-centred care with an emphasis on engagement of people in their own wellness. In his spare time, Mike enjoys travel and has been writing and performing music for most of his life.

- 1. What do you consider your greatest achievement? Aside from being a dad and telling excellent "Dad Jokes", I feel privileged for almost two decades to have been part of an Activist community of Health Care workers and other community-minded Canadians who engaged in a Coast to Coast effort to stand up for the rights and health care needs of newcomer Refugees in Canada.
- 2. **Guilty pleasure?** When my family is out of the house for the afternoon, I will pull out some '70s vinyl records, crank up the Pink Floyd, Steely Dan or The Clash, and sing along really loud ... there may also be Reese's involved.
- 3. What is the one thing you wish your patients knew? I am not sure if all my patients want to know this but I appreciate the observation by Voltaire that "the effective physician is one who can successfully entertain their patients while Nature takes its course."

- 4. Which movie or book can you re-watch or reread without becoming tired of it? I really like the simple beauty and musicality of the movie "Once". It is also a Tony-Award Winning musical and we just saw a great version at the Chemainus Theatre Playhouse!
- 5. What is your fondest vacation memory? As a child, family trips bundled into an overheated Ford station wagon and camping all over the country. We recreated that feeling a while back with my family on a vacation road trip from Kingston to Ocho Rios, Jamaica. And we all lived to tell about it.
- What is something that can't be taught and can only be learned with age? Nothing is as certain in medicine or life as it seemed at age 24.
- 7. What three events made the biggest impact on who you are today?
 - 1. Being born into a family with a Phys Ed/Health teacher for a Dad and a Public Health Nurse for a Mom.
 - 2. Picking "Rubber Soul" as the first record I ever bought.
 - 3. Saying "Sure" to the idea of getting set up on a blind date with Moira, who's been my life partner since that date.
- 8. What philanthropic or social cause is important to you? Why? For my entire career I have been engaged in work with, and for, and beside Indigenous Peoples in Canada and New Zealand. There is still much work to be done to reduce inequities. The impact of Colonization in the health care of Indigenous peoples is deep and pervasive, and must be acknowledged before it is mitigated.
- 9. What one question can you ask someone to find out the most about them? "What is it about you as a PERSON that I should know in order to help you better?" I still try to ask this as part of a medical history so I have an "anchor" to help understand the patient.
- 10. What's one small thing you would tell people to do each day that would greatly improve their life? Walk or otherwise move your body most days for at least half an hour, especially if it can be done with social interaction.

Caring for the Caregiver

"Many times, they're just thrilled to speak to someone who understands what they're going through and who can help relieve some of the pain points in their day to day interactions with their loved one," she says.

A common concern is that a caregiver feels guilty or manipulated into providing non-stop care. Talking to someone who understands, helps them realize they may be emotionally bankrupt and need to set boundaries. Sometimes what they need to hear is that if a loved one is (continued from pg. 1)

safe, it's ok to say no and carve out some time for self-care.

As Barb Hopkins helps others navigate the unique challenges

they're dealing with, she likes to remind people that, most of the time, a parent isn't trying to be difficult. "The frontal lobe shrinks with age, and that is where your filter lies. Once those physiological changes happen, your patience can be your biggest caregiving tool."



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