# CAREGIVER CONNECTION



— Let us help —



## It's not you: caregiving within a challenged healthcare system

Wendy Johnstone, Director of Programs and Innovation, Family Caregivers of BC (FCBC)

A million British Columbians are without a regular primary care provider and are experiencing long wait times at medical clinics.1 While government is working with its partners to improve access to primary care and bring fundamental change to siloed healthcare system, family caregivers continue to be the heroes as they pick up the pieces where healthcare sometimes can't. Day after day, the demands on caregivers grow as they continue to navigate complex systems, bridge information gaps, and provide more and more care to their loved ones.

And it's taking a toll. A big toll. Family caregivers are tired, frustrated, overwhelmed, and feel at a loss on what else they can do. It's incredibly unfair and yet, as one caregiver said to FCBC staff, "Life isn't fair, and yet you do what it takes".

How can you, as a caregiver, continue to provide care when it feels like you've hit a dead-end with services? Or when it feels like you've done everything you can but it still feels like it's not enough?

### In This Issue ...

- IT'S NOT YOU: CAREGIVING WITHIN A CHALLENGED HEALTHCARE SYSTEM
- ◆ EDITORIAL
- VOLUNTEER WITH US
- SPOTLIGHT ON FAMILY COUNCILS
- ♦ CAREGIVER CORNER
- **♦ DEAR CAREGIVER SUPPORT LINE**
- **♦ MIXED EMOTIONS**
- ♦ RESOURCES

Family Caregivers of BC is a registered non-profit charity dedicated 100% to supporting family caregivers.

BC CAREGIVER SUPPORT LINE:

1-877-520-3267

familycaregiversbc.ca

**Know it's not you.** Caregiving is becoming more and more complex with fewer available resources in a healthcare system facing challenges. Sometimes, there isn't a service or solution for your circumstances. As hard as that is, acknowledging this fact can bring some peace of mind that you are doing everything you can for the person you are caring for.

It's okay to have feelings. You're not alone in feeling frustrated, exhausted, angry, or overwhelmed. Many of us struggle to cope at one point or another as caregivers. It's normal to go through a range of emotions during difficult times. It also helps to remember that however you are feeling doesn't have to last. Give yourself some grace.

**Recognize how strong you are.** Day in and day out, you are tackling a caregiving role among many other responsibilities. Take a step back and reflect on your situation as a story with a strong and resilient main character finding a way through challenging times. Need a boost or reminder of how strong you are? Reach out to a trusted and caring friend or family member, connect with a peer group, or call our Caregiver Support line. When we feel less alone and supported, our resilience is strengthened.

**Share your experience**. We know it's a big ask. When you tell and share your story, it has such an impact on others. Never underestimate the power of change – big or small. Watch for opportunities to participate in research studies, provide feedback to your local health authority, or to share your story to support advocacy and policy work through FCBC's Caregiver Voices Panel. Your voice, your story is so important and can help transform our healthcare system.

We see and hear all the care you are providing, with love and because of relationships. You deserve more. There may not be a magic wand to make your caregiving circumstances easier, but know we are all here at FCBC striving to improve the landscape for all caregivers – from our services and programs to policy work to influence change. Reference: Two BC cities have longest wait times for walk-in clinics - Victoria Times Colonist

### Apply to join our team of volunteers at FCBC!

Family Caregivers of British Columbia's mission is to improve the quality of life for family caregivers through support, information, and education. We provide leadership to strengthen the voice of family caregivers and the significance of their role.

We have many different volunteer positions, ranging from a caregiver support group facilitator or cofacilitator, a caregiver ambassador, and a caregiver voice panel participant. Each position provides an opportunity to make a positive impact in a caregiver's life and our community.

To learn more about our volunteer positions, visit https://www.familycaregiversbc.ca/volunteer and subscribe to our Enews to stay in the know about upcoming volunteer opportunities!

"FCBC is an organization that practices what it preaches... Their care, empathy, compassion, and professionalism extends to their volunteers as well as their clients....Volunteers are acknowledged at every opportunity with kindness and gratitude. It's very special to be part of a group of people who are all working towards assisting caregivers along their journey. It is a privilege to me to be able to share in this work with the amazing people at FCBC."

From a current FCBC volunteer



### **Editor's Note**

Kate Landreth, Education & Learning Lead, FCBC

At some point in time, everybody will need a support person or be a support person, and FCBC knows firsthand the positive impact of thinking ahead about caregiving. Caregiving is not new, families in Canada are now providing more complex care for a longer period of time than ever before. Medical advances in our medical system is more successful in treating serious, acute illnesses and therefore people are living longer. However, this also means people are developing more ongoing or chronic conditions making it very challenging for them to care for themselves independently. This is one of the many reasons the health care system is stressed and stretched, which means more and more family members (particularly women) are taking on more caregiving responsibilities.

FCBC supports and prepares caregivers as they take on this important role. Being a family caregiver can be very rewarding; it can bring families closer and deepen relationships. It can bring immense satisfaction to make it possible for a care recipient to stay in their home and it can be rewarding to know that you are able to support them in carrying through their wishes. At the same time, caregiving can also be very stressful. Caring for a family member can create divisions within families, disrupt relationships, be exhausting and stressful, and involve some difficult decisions.

The fall Caregiver Connection issue has articles that reflect on the complexity of being a family caregiver, starting with our cover article, "It's not you: caregiving within a challenged health care system." Caregivers are facing an overtaxed and siloed system, resulting in hard to access services leaving them to feel they are not "doing" caregiving right. This article highlights that it is not you, or anything you are doing or not doing. Caregiving within a stressed health system is hard.

Next, we have Lisa Dawson, Chair of the Vancouver Coastal Association of Family Councils (VCAFC) share about the incredible work they are doing to support and give family caregivers a voice within long-term care (LTC) settings. This informative article outlines what family councils are, new regulations within LTC, and ways you can get involved in one.

We received feedback for more caregiver stories amongst our wonderful educational materials, and we are happy to share Helena Wiest's CBC first-person story, "A stranger at the end of the line gave me strength when I was at the end of my rope." She openly and vulnerably shares her caregiving experience and the positive impact of receiving "just in time" support that is non-judgmental and grounding from our BC Caregiver Support Line. In our 'Dear Caregiver Support Line' segment, our support team answers a question about increasing care needs and caregiving alone, which has led to caregiver burnout and exhaustion. Our support line shares the importance of having a circle of care for both the care recipient and the caregiver, extending the "it takes a village" concept to all caregiving situations, regardless of age. Lastly, the "Mixed Emotions of Caregiving" article outlines some challenges you can expect with caregiving, and ways to recognize and manage your emotional responses.

We hope you enjoy this issue and welcome your suggestions for future ones. Send us your thoughts through the 'contact us' page on our website: familycaregiversbc.ca/contact-us

From my heart to yours,

Kate

CAREGIVER CONNECTION familycaregiversbc.ca

### **Caregiver Corner**

# A stranger at the end of the line gave me strength when I was at the end of my rope

By Helena Wiest, with permission to re-publish her article from CBC First Person Stories

My phone chirped its bird call ring, startling me from the tangle of thoughts that were choking the light from my mind. I'd left a message at 8:54 a.m. with the Family Caregivers of BC, tearfully asking for someone to talk to.

I'm not normally the type of person to unburden my woes on anyone, least of all a stranger. But for 37 minutes, as a warm and gentle woman named Sage stayed on the phone, I sat weeping on the edge of the bathroom tub and unpacked the story of caring for my beloved husband whose neurological condition had rapidly deteriorated during the past two years.

For years, my husband had struggled with being disorganized in time and space, similar to someone who has ADD (which was an early diagnosis). He'd lost his sure and easy footing, often swaying when he walked because of his wide gait, and experienced various levels of bladder urgency.

In 2011, a fall in our kitchen finally led to a CT scan, which revealed he had extremely enlarged brain ventricles filled with cerebrospinal fluid that was not circulating as it should. The diagnosis — normal pressure hydrocephalus — explained the triad of affectionately named "wet, wacky, and wobbly" symptoms he'd been experiencing.

He had surgery to drain the fluid in his brain in 2011. That halted further damage and provided some improvement.

For 10 years, we enjoyed a reprieve of significant symptoms. Then something went amiss.

Where he was once sharp and witty, he struggled to keep up with conversations and took agonizingly long to form responses as he searched for elusive thoughts and words. James rarely left the safety of his armchair, walking with an unsteady gait and being prone to falls. Before I went to my job at the library, I prepared meals and left them out for him. He wouldn't have been able to process the steps to make something for himself and would go hungry instead. In fear, I bought him a membership to a medical alert system in case he fell when he was home alone and needed to call for help.

My youngish, 60-year-old husband was not the man I once knew. I was barely in my 50s, supposed to be in the prime of my life, but instead handling a life crisis that most would deal with in their retirement years.

Sage listened to me as I gulped out my story of anger at the medical system, at my husband and at my situation. The grief of losing pieces of my husband day by day was finally finding a voice, although not my own yet.

Years of checked emotions came out in my shaking sobs as I heard her affirmations of my efforts that often went unacknowledged.

Continue reading on page 9

CAREGIVER CONNECTION family caregivers bc.ca

### Caregiver Self Assessment

Start by responding to the statements below to recognize the positive steps you are already taking to ensure you stay healthy, and to identify areas where you might consider action to keep you resilient.

Circle "Yes" or "No" for each of the following statements:

- YES | NO I am satisfied with my overall personal health.
- YES | NO I have the skills and information I need to give the required care.
- YES | NO I maintain regular contact with family and friends, and make time to spend with them.
- YES | NO I can ask for and accept help when it's offered. I know I don't have to and can't do this
- YES | NO I can communicate effectively with the person I am caring for, as well as others involved in their care.
- YES | NO I am aware of community resources available to help support me in my caregiver role.
- YES | NO I am aware of caregiver support groups (locally or online) and have a supportive network where I can share my challenges and successes.
- YES | NO I make use of respite options available and take breaks from my caregiving responsibilities.
- YES | NO I have gathered information about the progression of my care recipient's disease so I know what to expect and can prepare in advance as best as I can.
- YES | NO I know how to navigate the healthcare system and who to ask if, and when I need help.

### What's your score?

Give yourself one point for each "yes" answer.

<u>8-10 points:</u> You are already taking several important actions to take care of yourself. Look closely at statements where you answered "No" and consider whether accessing more resources may be helpful.

<u>5-7 points:</u> You understand the importance of self-care, but are not always able to take action to support yourself. Consider any barriers you have to self-care and ask yourself whether these are external (you don't know about resources to help you) or internal (you have trouble asking for or receiving support). Sharing the care is essential to finding enough time and energy for yourself. Choose one "No" statement to work on this week.

<u>Fewer than 5 points:</u> Without contributing to your own well-being, caregiving quickly becomes overwhelming and unsustainable. Use this list of statements as a guide for creating a self-care plan. Start by learning more about the caregiver support resources available to guide you. Identify resources you're not currently using (family, friends, neighbors, etc.) to share the care and create some space for addressing your own well-being.

Adapted from Robert S Stall, M.D. (2002) Caregiver's Handbook, Buffalo New York

Find Resources to help you on Family Caregivers of BC's website: familycaregiversbc.ca Need Help now? Call our toll-free Caregiver Support Line: 1-877-520-3267

### A Spotlight on Family Councils

By Lisa Dawson, Chair of the Vancouver Coastal Association of Family Councils

Lisa Dawson is the Chair of the Vancouver Coastal Association of Family Councils and is Vice-President/Secretary for the Provincial Association of Family Councils: Independent Long-Term Care Councils Association of BC (ILTCCABC). Lisa is also a Co-chair of the long-term care home family council where her father has resided for the past 13 years. For seven years now, the entire care home community has enjoyed a collaborative, respectful, and productive relationship with their family council. The following is an article about her experience working with family councils.

Families and those of importance to residents in longterm care ("families," in short) are the unsung heroes of the long-term care provider team. These dedicated caregivers take on resident care tasks from feeding and hairdressing; to socialization and entertainment; to escorting to events and translation. They are invaluable to enhancing their loved ones' quality of care and life!

How can families work with a home's leadership to achieve the best possible experience for residents during their stay? The answer is family councils.

### What is a family council?

A family council is an independent, organized, self-led group of families, friends and persons of importance to residents in long-term care (LTC) who:

- Work to improve the quality of care and life of the home's residents; and
- Provide families with a voice in decision-making that affects them and their loved ones.

#### What do family councils do?

In my experience, there's no limit to what a family council can and will do to advocate for continuous quality improvement for their loved ones.

Here are a few examples:

Create the opportunity for members to meet in a safe environment that gives them privacy to openly discuss and plan for ways to improve residents' quality of life.

- Offer ongoing support for one another. Strength can be drawn from mutually shared experiences.
- Act on concerns affecting LTC home residents
- Collaborate and communicate with LTC leadership both in writing and in person.
- Serve as a sounding board and advisory body on new ideas and improvements.
- Advocate for positive changes to improve residents' quality of care and quality of life.
- Educate families about their own care home policy and procedures, the long-term care system in B.C., and community resources available.
- Quality is an intersection of a variety of indicators ensuring residents' dignity, choice, and autonomy.

"All of these things make a difference in the lives of residents, their families and staff, and the health care system that supports them," says Lisa. "It's the community of care coming together to improve health care!"

A Family Council Benefits the home and staff by:

- Promoting communication and collaboration with management and staff to build trusting relationships.
- Identifying concerns to be addressed and resolved before they become serious issues.

Continued on page 9

### Dear Caregiver Support Line

By Aaron Yukich on behalf of the CSL Team

My partner's care needs are increasing and I'm starting to feel overwhelmed. We are currently eligible for home care support two days a week but the rest of the time we're on our own. Currently I help with my partner's personal care needs, cook all the meals, drive to appointments, do the shopping and the list goes on. I'm tired, frustrated and I feel like I'm coming up short. Is it really meant to be this hard? Is there anything I can do?

With thanks. Feeling Tired and Overwhelmed

Dear Feeling Tired and Overwhelmed,

For many caregivers, feelings of being overwhelmed, frustrated, and being alone in the caregiving experience are all too common. Our current health care system is yet to reach a place of being able to address and coordinate the wide range of supports needed by care recipients and caregivers alike. Treating a medical condition is one thing but providing whole-person care to an individual as well as the accompanying needs of their caregiver(s) is something else altogether. The good news is that with a bit of planning, it is more than possible to create a wellrounded support network that can transform a frustrating and draining caregiving experience into a much more sustainable and meaningful one.

At FCBC we encourage caregivers to create a 'circle of care for caregivers', an informal support team made up of caring friends, family, and community members that come together to provide for the wide range of support needs experienced by care recipients and their primary caregiver(s). We are social beings, and our need for supportive relationships becomes that

much more important when we are faced with challenges in our lives. This is especially true for people who feel isolated or experiencing their own health concerns. While friends and family may be our natural go-to when building a circle of care for caregivers, we also encourage caregivers to expand their circle by seeking support from any other community members they may engage with. This could include co-workers, members of our faith-based congregation, or people you may know through a club or association.

Circles of care aren't a new concept and have existed as integral parts of indigenous cultures for millennia. Built-in support systems occur naturally within close-knit communities and multigenerational family households, however in Western modern culture, most people live within small nuclear family units, as couples, or on their own. Most of us no longer live in households with an integrated support system, and so we must now invite a circle to be formed around us. It is an intentional process, and one that draws on our intrinsic nature as human beings to support one another in times of need.

Our approach at FCBC is that a circle of care for caregivers is built around a multi-dimensional concept of wellness, providing for the physical, social, environmental, emotional, spiritual, and intellectual dimensions of health. The caregiver is positioned in the center of the circle and determines who gets invited in. Each member of the circle takes on a set of responsibilities that can range from preparing meals to driving to appointments, to providing companionship and/or respite support.

Continue on page 8

### Dear Caregiver Support Line continued

For caregivers who may have fewer friends or family members nearby, they can still call on support from a distance for things like providing a friendly phone call to the care recipient or assisting with scheduling appointments. Every minute of the caregiver's time that is freed up provides an opportunity for them to look after their own needs, be it connecting with a friend, doing an activity they enjoy, or simply taking the time to rest.

When creating a circle of care for caregivers, it can be helpful to assign one member to be the coordinator of the group. The coordinator can take charge of scheduling regular meetings and keeping track of who is doing what and when. This can save a tremendous amount of the caregiver's energy as information and updates can be channeled through one individual rather than many. We recognize that many people's circles may be smaller and that individual caregiver preferences may vary, so assigning someone else as the coordinator may not always be the way to go.

Caregiving is very personal, especially when it is happening in your own home, so it is normal to have some initial resistance to asking for help. However, when we gather the courage to share our experience and allow others to get involved, we not only open our homes to much-needed support, but we also open our hearts to meaningful connections and a sense of community. We all know the saying it takes a village to raise a child, and it's important that we consider extending this concept to all caregiving situations, regardless of age.

If you'd like to learn more about creating a circle of care for caregivers, or to talk to someone about your unique situation and the resources that may be available to you, please call our B.C. caregiver support line at 1-877-520-3267.

Sincerely,

**Caregiver Support Team** 

References: Roscoe, L.J. (2011). Wellness: A Review of Theory and Measurement for Counselors.

Sidney

### Join a Caregiver Support Group

Family Caregivers of BC has in-person and virtual support groups to help you find community support and meet your needs as a caregiver. Visit www.familycaregiversbc.ca/get-help/other-community-supports to find details on caregiver support groups in your community.

Support groups can be found in the following BC communities:

Maple Ridge

**Smithers** Abbotsford Mayne Island Port Alberni Gabriola Island Port Coquitlam Summerland Burnaby East Kootenay Nanaimo **Campbell River** Nelson Princeton Surrey West Kootenay Chilliwack North Vancouver Prince George **Terrace** Kamloops Comox Valley Oliver Quadra Island Vancouver Keremeos Coquitlam Pender Island Richmond Victoria **Lake Country** Cowichan Valley Penticton Salt Spring Island Langley Cranbrook **Pitt Meadows** 

**CAREGIVER CONNECTION** familycaregiversbc.ca

#### How can you get involved?

Get to know other families with a loved one in care to see if there's interest in starting a family council. Or, if there's already an existing family council, consider joining it. Reach out to the staff and administration at the long-term care home to see what their procedure is for supporting the establishment of new councils or transition to self-led councils. Contact your Regional Association of Family Councils and request their guidance and assistance. Independent Long-Term Care Councils Association of BC (ILTCCABC) iltccabc@gmail.com or contact Lisa at vcafc.regional@gmail.com

### **Caregiver Corner**

Continued from page 5

How I'd been strong to handle all that my family needed from me; how I raised our now 17-year-old son while I must've felt like a single parent; how the exhaustion of seeking answers from the medical professionals and feeling unheard must have been so discouraging.

She offered no solutions. Not one. Her voice was mellow and gentle, much like my own usually is, offering comfort in its gentle, assuring way. Even when I was silent, her calm voice anchored me in the present.



When I could at last take a deep breath without shuddering, I realized my storm had subsided, at least for that hour. My imagination pictures Sage with hair falling past her shoulders, roundish eyes filled with sympathy, and a softness in her face that opened to the world. I guess you could say I thought she'd look like an angel, because to me, that's what she was: an angel at the end of the line.

I never thought I'd be someone in need of calling a support line. I believed I had plenty of support to make it through any crisis — counseling, support groups, and some provincially funded programs for those with brain injuries. But the anonymity and complete freedom that came from telling a trusted stranger my rawest and most vulnerable thoughts was like blasting out the boulder that kept me locked in my own darkness. I'd never see this person, and so I spoke with free abandon.

Since that phone call with Sage, I've called their support line one more time, and thought about calling more times than I want to admit. Caregiving is a lonely journey, one that exhausts your resources on so many levels. In being able to speak honestly and vulnerably to a stranger at the end of the line, I came away feeling both heard and valued.

### **Mixed Emotions of Caregiving**

Adapted from FCBC Resource Guide for Family Caregivers

Caregiving can change your relationship with your family members, whether the person needing care is your parent, spouse, another relative, or an adult child. This change often brings up many issues and emotions. It is important to remember that everyone experiences caregiving differently.

#### What are some of the challenges you can expect?

- A shift in dependency usually results when parents become frail and need assistance to maintain their independence. As the parent-child dynamic changes, tensions or difficult emotions may arise.
- Finances become an issue when the care receiver's resources are insufficient to cover the expenses of
  daily living, health, and housing. Many families have trouble talking about money, and this important
  topic is often left until too late.
- Caregiving doesn't happen in isolation from other roles. The compounding effects of caregiving and
  other roles such as parenting, employment, maintaining a home and social ties can increase stress and
  feelings of isolation.
- Lack of knowledge about the aging process makes decision making difficult, particularly when it is hard to know if the care recipient's behaviour is normal or a cause for concern.
- Emotional responses to the changes that accompany aging and frailty and the demands of caregiving can surprise many.
- Lack of experience about how the health care system works and community resources can result in inappropriate expectations from the "system," poor decision-making, time-consuming run-around and inflated emotional states during crisis.
- Lack of planning for the future is common and can result in the avoidance of important discussions.
   Typical topics that are helpful to discuss include: housing needs as frailty increases; finances; how caregiving will be carried out in the family; the care receiver's preferences regarding heroic measures; and dying and death, after death services, power of attorney and distribution of the estate.

#### Recognizing your emotional responses

Being a caregiver can sometimes feel like one big emotional roller coaster. There are many ups and downs with conflicting emotions rising to the surface. It's natural and normal for caregivers to experience a range of emotions. Some suggestions for managing your feelings include:

- Practicing self-compassion. Self-compassion is the ability to notice when you're struggling to see and hear yourself and to feel tenderness for yourself in difficult moments.
- Journaling to express your thoughts, feelings, and concerns.
- Talking with people that you trust and who can really listen to you. Support groups are a safe and trusted place for caregivers to share their feelings and receive support.
- Asking yourself, "What are your strong feelings about? What are they telling you? What is the purpose
  of these feelings? What old patterns or messages am I repeating?"
- Distinguishing between what you can do something about and what you can't do anything about.
- Practicing "thought stopping" exercises for negative and catastrophic thinking patterns.

CAREGIVER CONNECTION familycaregiversbc.ca

### **DISEASE/CONDITION SPECIFIC CAREGIVER SUPPORT**

Here to Help (Mental Health) 310-6789 **ALS Society of BC** heretohelpbc.ca www.alsbc.ca/ 1-800-708-3228 (no area code; free available 24 hours) **Alzheimer Society of BC** alzheimer.ca/bc/en 1-800-667-3742 **Huntington British Columbia Resource Center** First Link Dementia Helpline 1-800-936-6033 604-822-7195 chd.med.ubc.ca/home/hsc-resource-centre/ **BC Brain Injury Association** brainstreams.ca 604-984-1212 **MS Society of Canada** 1-800-268-7582 mssociety.ca 1-888-888-0029 **B.C Schizophrenia Society** bcss.org Parkinson Society B.C. 1-800-668-3330 parkinson.bc.ca **BC Cancer Agency** bccancer.bc.ca/contact **Stroke Recovery Association of BC** 1-888-313-3377 strokerecoverybc.ca PROVINCIAL SUPPORT RESOURCES 1-888-495-8501 Crisis Centre BC **Anti Fraud Centre** 1-800-SUICIDE antifraudcentre.ca 1-800-784-2433 Crisiscentre.bc.ca BC211—non-medical **Family Caregivers of British Columbia** www.bc211.ca familycaregiversbc.ca Caregiver Support Line (toll free) 1-877-520-3267 **BC Association of Community Response Networks** bccrns.ca / info@bccrns.ca **Find Support BC** findsupportbc.com **B.C. Health Authority General Inquiry Lines** Fraser Health 1-855-412-2121 **First Nations Health Authority** 1-866-913-0033 Interior Health 250-388-2273 or 250-980-1400 fnha.ca Island Health 1-888-533-2273 HealthLinkBC—medical—healthlinkbc.ca Vancouver Coastal Health 604-263-7377 Call 811 any time 24/7 to speak with a nurse. Northern Health 250-565-7317 Pain BC 1-844-880-PAIN **B.C. Ministry of Health** painbc.ca 1-844-880-7246 www.gov.bc.ca/health Visit www.healthlinkbc.ca/healthtopics and **Nidus Personal Planning Resource Centre** enter "caregiver in the search field nidus.ca / info@nidus.ca Visit www.patientsaspartners.ca for the free self-management activities **Seniors First** www.seniorsfirstbc.ca

**B.C. Palliative Care Benefits** 

www.health.gov.bc.ca/pharme/outgoing/\_palliatibe.html

**BC Seniors Guide** 1-877-952-3181

gov.bc.ca/seniors-guide

PDF Available in English, Chinese, French, Korean, Vietnamese, Punjabi and Farsi, Hard copy available

SAIL—Seniors Abuse and Information Line

Vancouver Metro 604-437-1940 Toll Free 1-800-437-1940

UBC Pharmacists Clinic 604-827-2584

pharmsci.ubc.ca/pharmacists-clinic

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### We Can Help Right Now!



BC Caregivers Support Line 1-877-520-3267 Monday to Friday 8:30 a.m. to 4:00 p.m. Toll-free, here to support you!



— Let us help —

info@familycaregiversbc.ca

www.familycaregiversbc.ca

### Switch to our e-Newsletter!

If you'd like to stop receiving a paper copy, please let us know at info@familycaregiversbc.ca.

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