

# CAREGIVER CONNECTION



Family Caregivers  
of British Columbia

— Let us help —

SUMMER 2022

VOLUME 36 ISSUE 3



## Parallel Paths: The Changes Experienced in the Caregiving Relationship.

By Elizabeth Bishop, author of *Conscious Service*

Becoming a caregiver is often motivated by deep love and affection. But it can also feel like an obligation or duty. Sometimes, it's a mixed bag of emotions swinging from one end of the spectrum to the other.

Some caregivers are instantly aware of the precious gifts in caregiving, while others may never find those treasures. Most experience loss and grief in the journey. While caregivers process all the changes, so too do those on the receiving end. Even while the experiences are unique to each, the journey in many ways is shared.

### Little Changes Add Up

There is nothing like caregiving for someone with extraordinary needs to bring us face to face with loss -- both the current reality and the anticipation of it. Knowing that someone is near the end of their lives can make this time quite poignant and potentially very challenging. Caring for someone who may still live a long time, but who might be at high risk for complications or early death, can create a kind of hyper-alert response in the caregiver.

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

BC CAREGIVER SUPPORT LINE:

**1-877-520-3267**

[familycaregiversbc.ca](http://familycaregiversbc.ca)

# Editorial for Summer 2022

by Victoria Lougheed, Education & Learning Lead, FCBC

Elizabeth Bishop, who has written about her caregiving experiences in, *“Conscious Service: Ten Ways to Reclaim your Calling, Move beyond Burnout, and Make a Difference without Sacrificing Yourself”* starts our Summer newsletter in style. In her article, Elizabeth speaks to the challenges caregiving brings as we move along the trajectory with our care recipients.

Good mental health is fundamental to being a good caregiver. As we balance our caregiving relationship, boundaries need to be identified and shared, especially when things change for us or our care recipient. The article on boundary setting comes from our archives. Our Caregiver Well-Being Project is reviewed by Sage Schmied. The project was very successful, and we are pleased to share it with readers. The Dear CSL column helps a caregiver navigate a setback. Rick Lauber provides some self-care insights about the benefits that journaling can provide. Patricia Smith, author of the book *“The Caregiver’s Companion,”* brings a light-hearted look at how aging alongside our care recipients can provide some unexpected challenges of its own. It’s so important to hang onto our sense of humor!

We hope you enjoy the newsletter this summer. Please don’t hesitate to contact us with any questions, comments or ideas you’d like to share. We’re always here for you!

May the summer warmth and sunny days bring you peace and happiness!

Victoria

## Join a Community Caregiver Support Group

Family Caregivers of British Columbia 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](http://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 B.C. communities:

Abbotsford	Delta	Nanaimo	Richmond
Burnaby	Gabriola Island	North Vancouver	Salt Spring Island
Campbell River	East Kootenay	Oliver	Sidney
Chilliwack	West Kootenay	Pender Island	Smithers
Comox Valley	Keremeos	Penticton	Summerland
Coquitlam	Lake Country	Port Alberni	Surrey
Cowichan Valley	Langley	Port Coquitlam	Vancouver
Cranbrook	Maple Ridge	Princeton	Victoria
	Mayne Island	Prince George	

## Parallel Paths: Continued from Page 1

Caregivers often witness loss of function in those they care for. This truth can cause fear and resistance that may include denial of the situation. Sometimes “this is not happening” mantras can be soothing for a while — until it isn’t. Then the caregiver is called to accept a particular reality that may add to their caregiving in ways they aren’t prepared for. Ways that impact their own daily functioning.

Accepting something does not mean we need to like it. We can accept what is happening and honour our discontent. When we can’t do things the way we have always done them, we have an opportunity to hone our problem-solving skills and get creative in the pursuit of a solution.

### Changing Independence and Freedom

Caregivers often struggle as they witness alterations of independence in their family member or friend brought on by changes in function. Erring on the side of caution, it is easy to rush to protect. We can become very focused on physical safety and health at the expense of a holistic quality of life.



When we lose our independence and freedom, our quality of life can quickly deteriorate. Without connection to self, inspiration, self-efficacy, and autonomy, loss of hope and joy all but disappear. Joy is a facet of well-being that can be easily overlooked when the focus is on survival.

At the same time, caregivers are also taking a hit to their freedom. Gone are the days of long weekend road trips off the grid. Dream vacations are postponed, career paths interrupted, and never mind the shift in daily life to accommodate more people, and unanticipated events. It can feel like life has been stolen out from under you. The fact that you don’t like it only leads to guilt.

We are invited now to discover a deeper meaning of freedom in our lives, to explore where new choice points exist, and to decide how we will respond now, both internally and externally. There is an opportunity here to deepen our capacity to have faith in what is unseen and tap into intuitive knowing on levels not previously experienced.

### Changing Relationships

As care needs increase, relationship dynamics change. Role reversals, intimacy interruption, and increased focus on care details at the expense of other forms of connection have potentially devastating implications. At times, it can feel as though the former person is no longer and everyone involved is finding new footing in a relationship with an intimate stranger. You’ve shared lives together, but now everything is different.

Letting go of the previous versions of identity for both self and other, as well as your shared story, is no easy task. Be gentle with yourself and the process. Grieving the past and letting it go opens the space for renewal of relationships. When everything is changing, we can access the gift of the unknown with a heart seeped in fear or one filled with hope. Forging ahead with curiosity might unearth a treasure you never knew existed.



# 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 alone.
- 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.

8-10 points: 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.

5-7 points: 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.

Fewer than 5 points: 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](http://familycaregiversbc.ca)

Need Help now? Call our toll-free Caregiver Support Line: 1-877-520-3267

# The Importance of Healthy Boundaries in Caregiving

From the Family Caregivers archives, edited by Victoria Lougheed

Healthy boundaries let caregivers maintain an emotional connection to the person they are caring for without the negative impacts of discomfort, resentment, or guilt. If you feel taken advantage of, unheard, or unappreciated, it may be a flag that you're allowing a boundary violation. Perhaps the person you are caring for is imposing their expectations, views, or values on you.

## Whose issue is this?

It takes two for a boundary to be violated. If you can understand why you allow it, you have the option to change. Look for feelings of guilt, or a need to please or rescue. These occur around boundary violations. Anger, negativity, or pushback from your care recipient may be a sign that you are pushing their boundaries. Are you respecting their need for independence, autonomy, and self-direction?

## Know your limits.

List your physical, emotional, and mental limits. Consider what you can tolerate and accept. Then identify what makes you feel uncomfortable or stressed. The feeling of discomfort is a sign that a boundary is being pushed.

## Caring within a boundary.

Determine what parts of caregiving only you can fulfill. Ask yourself if someone else can meet the care recipient's needs. Discuss with your care recipient what you can and can't (or won't) do. Explain why you are setting the boundary: work, stress, health, other family obligations, etc.

Expect pushback if it means bringing others into your care recipient's life. This will be a change for both of you. Validate their concerns but maintain the boundary. Connect with our Caregiver Support

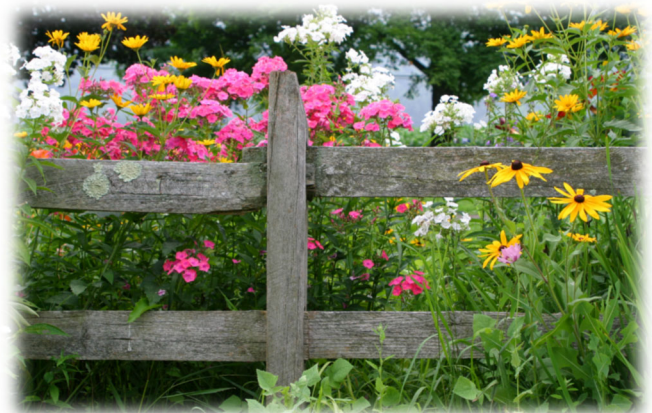
Line to get advice or support around navigating this with your care recipient.

## Give yourself permission.

Caregivers often worry about the other person's response when a boundary is set and adhered to. Caregivers feel they "should" be able to cope with a situation even when they feel their boundaries are violated. Maintaining a boundary gives you the energy and perspective to better handle your role as caregiver.

## Find support.

A group of peers to talk to or a close and trusted confidante makes it easier to set boundaries and be accountable. It takes courage and practice to set boundaries and stay the course. FCBC has support groups in person and virtually to give you that group of peers to turn to.



## Self-Respect.

Being a resilient caregiver is about recognizing the importance of our own lives, family, and work. It is striving towards caregiving within those limits. Setting boundaries allows you to continue caring with compassion and devotion and not feel lost or swallowed up by the caregiving role. Boundaries are a sign of self-respect.

# The Greater Victoria Caregiver Well-Being Project

By Sage Schmied, Caregiver Support and Resource Specialist

*“This program was invaluable. It really brought me back from the brink emotionally; I was feeling like I was headed for a crash. I'm so grateful! Thank you.”*

In December 2020, Family Caregivers of BC conducted a B.C.-wide survey and found that the COVID-19 pandemic had significantly impacted mental health for caregivers. With this in mind, FCBC recognized the need to offer multiple options for caregivers to support well-being and mental health. The Greater Victoria Caregiver Well-Being Project was born. With funding from the United Way, we were able to offer something new: group sessions led by a clinical counsellor, that focused on skills and tools to improve wellbeing. I was interested in helping to coordinate this project as it seemed like it would have lasting benefits for those who participated. Up to that point, I had been working casually on the Caregiver Support Line and was excited to support caregivers in an additional way.



The Well-Being Project, as it came to be known, focused on exploring tools and skills relevant to the caregiving experience, as well as increasing connections to resources and community. This was done by offering a seven-week group session, where caregivers would come together around a specific weekly topic, learning and sharing their experiences. Tania Suzuki, a registered clinical counsellor, designed and led the project. Each topic was unique and meaningful to the experience of caregiving. Topics covered included emotions, communication with self and others, self-care, making friends with stress, understanding pain, other protective factors, and boundaries. Participants began and concluded sessions by coming together as a group to share experiences and learnings. Something that stood out to the participants was thinking about how our emotions serve us; specifically, that anger is an important emotion that communicates how our needs matter. When discussing boundaries, participants practiced using ‘I statements’ – a simple way to set boundaries and help focus on how to communicate needs as caregivers. The sessions also included relaxation and somatic practices which the group valued.

There were so many great takeaways, and it was incredibly meaningful to be a part of such a wonderful group of people. This project never felt like work to me because of how supportive everyone was and how each week there was something new and impactful to learn. The caregivers made meaningful connections, with the group participants aiming to meet outside of the sessions. For me, the honesty and willingness of each person to show up to this group and share demonstrates how groups can positively impact wellbeing. This is encapsulated by this quote from a participant, *“I believe every caregiver should take a course like this, if you learn how to take care of yourself you will be a better caregiver and also know where to get support when you need it!”* The Greater Victoria Caregiver Well-Being Project was one of the most grounding experiences I have had at Family Caregivers of BC, and I would jump at the chance to do it all over again. A huge thank you to our sponsors and everyone who was a part of these sessions.



# Keeping a Caregiving Diary: The Benefit of Journaling

By Rick Lauber

## Why journal?

Ask any family caregiver about his/her experiences and you'll likely hear these defined as "stressful", "demanding", and even "unbearable". With helping my own aging parents, you won't hear any argument from me that assuming new responsibilities, finding balance, and facing a loved one's physical/mental decline can easily add up to become too much to handle. But what is the answer? Finding a means to cope.

While many different coping strategies exist, my solution was to journal. I have long enjoyed writing and this struck me as a logical option as my parents aged and my caregiving responsibilities began to weigh more heavily. Writing about my thoughts, feelings, and experiences proved to be a good choice as a safe and effective means to help me better manage.

If you are drawn to writing (or would like to experiment with it), here are a few recommendations to get you started and keep you on track:

## Resist writing the whole story:

Opening the floodgates completely about your caregiving role is both unnecessary and unwise. Instead, focus on just one event, memory, or feeling instead to not become overwhelmed. Personally, I have written about a family Christmas dinner, my participation in a bereavement group, and my father's favourite hiking hat. Discussing only one topic, rather than many, is easier for both the writer and the reader. What you say will be far more important than how much you say.

## Overcome writer's block:

Writers, at all levels, can struggle with facing a blank page. If you don't know where to begin or what to write next, don't force the issue. A beautiful thing about writing is that it is meant to be enjoyable. Free writing can be a wonderful exercise to get you started. Sit down and write about whatever comes to mind. Don't edit. This doesn't have to be grammatically correct or even make sense ... it will often stir up other ideas.



Another answer may be distraction. I like to walk. Breathing in fresh air and getting some exercise can often generate writing ideas. Yet another method is to ask yourself the journalistic "5 W's" (who, what, where, when, why, and how) to get started. Prompting questions could be, "What did you do with Mom/Dad today?" "Who helped you the most today to provide care?" or "How did you feel during your visit with Mom/Dad?"

*Continued on page 9*

# Dear CSL: Bouncing Back from a Decline or Setback

By Wendy Johnstone for the Caregiver Support Line

Dear CSL: *I'm caring for my wife who is living with Alzheimer's Disease. She is very functional and maintains a high level of independence. But it feels like some cracks are starting to show. Three months ago she fell and hit her head hard resulting in a big decline in her memory. We had an appointment with the Geriatric Outreach Team and they did a cognitive assessment and her scores showed a noticeable drop from her previous assessment. I feel devastated about this news, and it feels like such a setback for us. How do I "bounce back" from this setback?*

Yours Truly,

Tigger Wanna Be



As caregivers, we do all that we can to help support our loved ones to remain independent and with the best quality of life possible. It's hard to see our loved ones change as a disease progresses or as a result of an unexpected event. Unfortunately, setbacks happen, and we often can't predict or control them. We can try to respond to setbacks in ways that minimize the stress they cause us and our loved ones. We hope these ideas help support you in moving forward from your setback in caregiving (or in general from life's setbacks!)

**BREATHE:** Breathing is one of the best ways to give us pause, perspective, and time to think. One idea that emerged from our team is hitting the BREATHE app on a smartphone or smart-watch for one minute. For some, it's counting 10 breaths in and out, or meditating for a few minutes

**TIME:** Give yourself time to feel. It's okay to take time to grieve a change or loss in the caregiving relationship. Be mindful of your feelings, and encourage yourself to acknowledge that life is imperfect. Hold space and comfort for yourself in difficult times. It's a fine balance. Research shows the importance of not staying too long with negative thoughts.

**INTENTION:** Using intention is a great way to coach ourselves through challenges. A personal mantra or supportive reminder helps nurture us. When feeling overwhelmed, try saying a phrase like, "This is hard, and it feels hard for me. I'm doing my best right now. What can I do for myself in this moment?" Setting an intention clarifies what is most important for the moment. It gives us permission and time to step back, check in with ourselves before taking on an interaction or task. [Here](#)\* is a great resource for setting intentions. See below for a link.

**PRIORITIZE:** Setbacks often mean we need to revisit priorities or change ways of doing things. Find a quiet place to list your priorities, or talk through the implications with a friend, or our Caregiver Support Line. This can help you understand what it means for you and your loved one. Break down tasks into manageable pieces to address one-by-one. Look at what you can or can't do in light of the change.

**ASK FOR HELP:** Don't be afraid to reach out for support from family, friends, health professionals, or community agencies like FCBC. Many caregivers have been, or are currently, in similar situations. They can offer ideas on how to manage your setback.

\*Resource: <https://www.familycaregiversbc.ca/wp-content/uploads/2020/05/Setting-Intentions-April-2020.pdf>



## Keeping a Caregiving Diary: Continued from page 7

### Decide to share – or not to share:

What you choose to write is entirely your choice – as is what you choose to do with your writing. Keeping your personal thoughts (and, perhaps, uncomfortable caregiving matters) private is understandable, but I would urge you to share. After starting with personal journaling, I realized that what I had experienced and learned from could help many others as prospective, new, or even current caregivers. Nervously, I chose to submit my stories for publication in a local senior's newspaper. These stories became more frequent and developed as the platforms for my two published caregiver's guidebooks! Going public with what you write is not obligatory but doing so can raise awareness of caregiving issues and help others better help you.



Grab a pen and notebook (or your laptop computer)! Writing it out – or typing it out – can be enjoyable, therapeutic, and valuable to your own mental health.

*Rick Lauber has written two books, **Caregiver's Guide for Canadians** and **The Successful Caregiver's Guide** as valuable resources for prospective, new, and current caregivers. He has also served as a voluntary Board of Directors member for **Caregivers Alberta**. [www.ricklauber.com](http://www.ricklauber.com).*

## Emotions of Caregiving: Shock of a New Diagnosis

By Mechthild Maczewski (she/her)

Caregiver Support Line Coordinator

### Processing

The words float by, yet hit hard  
Lifting me into the realm of the surreal  
Not a surprise  
Yet shocking  
Numb

What now?  
What next?  
Breathe. Sigh.  
Ground.

What is my role?  
What can I do?  
What can't I do?  
What's happening??

Another chapter in my journey  
Going into unknown places  
Retreating into safe spaces  
Welcoming and fearing all

Feelings, thoughts, senses  
Swirling, flooding  
Grasping, already grieving.  
Here we go.



# Loss of Traction

By Patricia Smith, author of the recently published book *"The Caregiver's Companion"*

Our 2000 Toyota Avalon has passed the 284,000 kilometer mark. She has been a marvelous car, living up to her reputation as one of the most reliable vehicles on the road. My husband is comfortable in this car, unlike many of the newer models. But alas, like me, our Avalon is now showing signs of her age. She refuses to lock or unlock the passenger door with the fob. I now have to perform these operations manually. I could liken her failure to respond to my signals to my failure to respond to my husband's remarks to me when the TV is on or when he is in another part of the house and calls for me. It seems my hearing is just not what it used to be.

I could keep drawing parallels between the aging car and me, but I suspect I have made my point. We are both getting old, although I still think we look pretty good, especially considering our respective ages. The bald truth remains: the car and I are spending more time with our mechanic, Bill, than we once did. On my last visit in November for a new battery, I remarked to Bill that I had his Car Clinic number memorized.

He laughed and said: "It's when I have your number memorized that you need to worry."

I laughed, too, but knowing how fleeting my memory can be—a fact my husband would be more than willing to attest to—I decided to program the Car Clinic number into my a vintage Motorola V551 GSM flip phone circa 2005.

On my September regular service visit to the Car Clinic, Bill had suggested that she would soon need a new timing belt in about a year. (Ideally I would like one for me, too.)

Now it's January and my husband has heard a suspicious whirring under the hood just after I have put her into reverse and am about to accelerate. It's time to call Bill for an estimate on a timing belt. I flip open my cell phone, locate the Car Clinic entry, turn off my cell phone, and dial his number on my land line. Bill answers. I identify myself and begin to explain the current problem. In the background at the clinic I can hear another phone ringing.



"Just a minute, please," Bill interrupts. "I've got a call on the other line."

There's a short pause and he returns.

"There was no one there, but here's the weird thing: my caller ID says it was from another Patricia Smith."

"Another Patricia Smith?" I ask. "Now how strange is that?" In a trice I consider the astronomical improbability of two people with the same name calling the same Car Clinic at exactly the same time. Could the universe be collapsing into an alternate dimension? Just like me and our Avalon?

"I'll say!" says Bill. "She was calling from . . ." and he proceeds to recite the number of my flip phone, which I assumed I had shut off, but must have pushed the wrong button.

"Life certainly throws up some odd coincidences" I say. "So . . . How much will a new timing belt cost?"

# Disease/Condition Specific Caregiver Support

## **ALS Society of BC**

1-800-708-3228

## **Alzheimer Society of BC**

1-800-667-3742

## **First Link Dementia Helpline**

1-800-936-6033

## **BC Brain Injury Association**

604-984-1212

## **British Columbia Schizophrenia Society**

1-888-888-0029

## **BC Cancer Agency**

[bccancer.bc.ca/contact](http://bccancer.bc.ca/contact)

## **Here to Help (for Mental Health)**

310-6789 (no area code; free available 24 hr)

## **HSC British Columbia Resource Center**

604-822-7195

## **MS Society of Canada (B.C.)**

1-800-268-7582

## **Parkinson Society B.C.**

1-800-668-3330

## **Stroke Recovery Association of BC**

1-888-313-3377

## Provincial Resources

### **Anti Fraud Centre**

[www.antifraudcentre.ca](http://www.antifraudcentre.ca)

1-888-495-8501

### **BC 211 - non-medical**

[www.bc211.ca](http://www.bc211.ca)

### **B.C. Health Authority General Inquiry Lines**

Fraser Health

1-855-412-2121

Interior Health

250-388-2273 or 250-980-1400

Island Health

1-888-533-2273

Vancouver Coastal Health

604-2637377

Northern Health

250-565-7317

### **B.C. Ministry of Health**

[www.gov.bc.ca/health](http://www.gov.bc.ca/health)

- visit [www.healthlinkbc.ca/healthtopics](http://www.healthlinkbc.ca/healthtopics) and enter "caregiver" in the search field.
- visit [www.patientsaspartners.ca](http://www.patientsaspartners.ca) for the free self-management activities

### **B.C. Palliative Care Benefits**

[www.health.gov.bc.ca/pharme/outgoing/palliative.html](http://www.health.gov.bc.ca/pharme/outgoing/palliative.html)

### **BC Seniors Guide**

[www.gov.bc.ca/seniors-guide](http://www.gov.bc.ca/seniors-guide)

1-877-952-3181

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

### **Crisis Centre BC**

[crisiscentre.bc.ca](http://crisiscentre.bc.ca)

1-800-SUICIDE

1-800-784-2433

### **Family Caregivers of British Columbia**

[www.familycaregiversbc.ca](http://www.familycaregiversbc.ca)

Caregiver Support Line:

1-877-520-3267

### **Find Support BC**

[findsupportbc.com](http://findsupportbc.com)

### **First Nations Health Authority**

[www.fnha.ca](http://www.fnha.ca)

1-866-913-0033

### **HealthLinkBC - medical**

[www.healthlinkbc.ca](http://www.healthlinkbc.ca)

Call 811 any time 24/7 to speak with a nurse.

### **Here to Help - mental health**

[www.heretohelp.bc.ca](http://www.heretohelp.bc.ca)

### **Pain BC**

1-844-880-PAIN

[www.painbc.ca](http://www.painbc.ca)

1-844-880-7246

### **The Nidus Personal Planning Resource Centre**

[www.nidus.ca](http://www.nidus.ca) | [info@nidus.ca](mailto:info@nidus.ca)

### **Seniors First**

[www.seniorsfirstbc.ca](http://www.seniorsfirstbc.ca)

### **SAIL - Seniors Abuse & Information Line**

Vancouver - Metro

604-437-1940

Toll Free

1-800-437-1940

Language Interpretation (9am-4pm Mon-Fri)

[www.seniorsfirst.ca](http://www.seniorsfirst.ca)

### **UBC Pharmacists Clinic**

[www.pharmsci.ubc.ca/pharmacists-clinic](http://www.pharmsci.ubc.ca/pharmacists-clinic)



# We can help RIGHT NOW!



**BC Caregiver Support Line 1-877-520-3267**

Toll-free, available Mon/Wed/Fri at 8:30 am-4:00 pm and  
Tues/Thurs at 8:30 am - 7:00 pm



**info@familycaregiversbc.ca**



**www.familycaregiversbc.ca**



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