# CAREGIVER CONNECTION



— Let us help —

**WINTER 2023** 

**VOLUME 37 ISSUE 1** 



#### **Top Caregiving Resources in 2022**

By Kate Landreth, Education & Learning Lead, FCBC

As the days become shorter, the nights cooler, and we embark on a New Year, we wanted to share the positive impact Family Caregivers of BC has had on family and friend caregivers. Our mission is to improve the quality of life of family and friend caregivers through support, information, education and leadership. Here is a recap of the top five resources that caregivers found impactful this past year.

Are You A Caregiver? Many times a friend or family member starts supporting someone in their life with a few errands here and there, and then it quickly escalates to daily tasks like groceries, meals, medication management, coordinating support services or appointments and much more. Many caregivers do not identify with the term, as they may not know the definition of a family caregiver! 'Are you a Family or Friend Caregiver?' is a top website resource. It allows one to understand the role of a caregiver and includes supportive resources. In addition, we encourage everyone to check out our Resilience Strengths quiz.

> Are You a Family or Friend Caregiver? https://bit.ly/3VNfO9N Resilience Strengths Quiz https://bit.ly/3GYvfrs

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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

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#### **Editorial for Winter 2023**



by Kate Landreth, Education & Learning Lead, FCBC

#### "I realise there's something incredibly honest about trees in winter, how they're experts at letting things go." Jeffrey McDaniel

This quote resonates with my current life transition, from my many walks amongst the trees with my newborn to now - one year later - my maternity leave has come to an end, and I am happily back to my role as Education and Learning Lead with FCBC. Although this work transition is welcomed, like many life transitions it is met with introspection, some sadness, and the practice of letting go to allow something new to unfold. More than ever, this past year I have drawn upon nature's wisdom and seasonal teachings to help guide my own caregiving experience. Letting go of expectations or how life 'should' go has been one pivotal lesson this year.... maybe you can relate?

In order to move forward into the New Year with purpose and focus, I have found it beneficial to pause and take inventory of what I have accomplished, personal successes and moments of joy. It is so easy to become fixated on mistakes or hardships, rather than noticing and celebrating what is going right or what I have learned.

I encourage you to pause and consider your own past year review. Grab your day planner, journal or piece of paper and take a moment to reflect on these questions. What were your top moments of joy this year? What were your successes? What were your greatest challenges? What lessons did you learn this year? And now, as you move into the new year, what are your intentions or vision? Is there a word that could describe your intention for 2023?

Family Caregivers of BC is reflecting on our mission and vision, celebrating our team members and our successes in supporting family and friend caregivers. It is with a heavy heart that we share the loss of a dear friend and colleague, Jane Sheaff, to cancer. If you had the good fortune of being on the receiving end of the Caregiver Support Line with Jane, you could feel the warmth, care and compassion she exuded. She truly was an exceptional person, and we share our appreciation and loving memories of her in 'A Tribute to Jane Sheaff' on page 5.

Our cover article shares our top five caregiving resources of 2022 and then we have two articles that address caring from a distance. "Dear Caregiver Support Line" on page 6 shares a caregiver's worry about caring from afar and our support team provide feedback and tips on this topic and on page 8 Karla Wilson (our dear colleague) shares her long distance caregiving experience with her mother. Lastly, 'Walking a Mile in Their Shoes- Responding with Empathy' on page 10 is pulled from our recent webinar "Self-Reflection—The Basis for Being an Empathic Caregiver" and shares a technique to help caregivers respond with empathy.

We trust these articles will provide some comfort and support and know you are not alone. We see you and we are here to support your wellbeing.

From my heart to yours,

Kate



Many caregivers experience financial stress associated with providing care for someone, in fact lack of funding and the need for financial assistance are the issues Canadian caregivers identify as their biggest stressors. FCBC has put together an 'Overview of Financial General Resources, Tax Benefits and Credits for Caregivers 2022' and this resource has been a top resource

Overview of Financial General Resources ... for Caregivers http://bit.ly/3FmCPuR

The Intensive Journal Workshop for Caregivers facilitated by Bill Israel has received resounding praise. These sessions provide a safe space for participants to write and self-reflect with no judgement and lots of self-compassion. Caregivers have expressed they are able to have brief respite from stress and fatigue, while improving their body and emotional awareness. If you would like to learn more about upcoming workshops, please contact Lycia Rodrigues at cgsupport@familycaregiversbc.ca



"It was the most rewarding thing I have ever done as a caregiver. I am not a writer or a book worm...it's been a comfort to be able to express my emotions and put them to paper..."



Creating a personal caregiving plan that is tailored to your emotional and physical needs helps with contingency planning and burnout prevention. 'Caregiver Support Plan: Make it Personal' is a flipbook with activity sheets that provides step-by-step instructions on how to curate a plan unique to you. This has been a very useful tool caregivers use to support their planning and understanding their own caregiving needs.

One of the biggest challenges for caregivers is getting their needs met because often the needs of their care recipient are greater than the caregivers. However, it is okay and needed to set ground rules in the caregiving role. The webinar, "Where to Draw the Line: Boundary Setting for Caregivers" is a big hit, because it discusses boundaries in a practical way to help set ground rules between the caregiver and the care recipient.



Webinar—Where To Draw The Line: Boundary Setting For Caregivers https://bit.ly/3B4kuQF



### 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 Tribute to Jane Sheaff

By: Janet McLean, Lycia Rodriguez, et al.

Our Caregiver Support Line lost a treasured team member on November 18, 2022. Jane Sheaff will be a familiar name to many of our readers in Greater Victoria. Jane was the Executive Director of Seniors Serving Seniors in Victoria for 25 years. In that role she solidified the organization and it's mission within the community. Under her direction, the volunteer-based telephone support program (Seniors Link) flourished. Jane also expanded the Return to Health program that is operated in conjunction with Island Health. Among her most noteworthy achievements, Jane oversaw the publication of 12 issues of the



famous Blue Directory of services and resources for seniors living in and around Victoria, long considered a bible for the public and professionals working in the health and social sectors.

When Jane retired from Seniors Serving Seniors, we approached her to join our Caregiver Support Line team. We were honoured to have her come onboard in July 2019. As always, Jane added in so many ways. She contributed valuable insights into the needs of seniors and the kinds of resources they need — which of course impact directly on caregiving. Her empathetic listening and sage advice on the Caregiver Support Line were often specifically mentioned in caregiver feedback we received. As a team member, Jane was always willing to help however she could — always thinking of others before herself.

Jane leaves an indelible hole in our team, and forever holds a spot in our hearts. We were so lucky to have had her among us at FCBC.

#### In Blackwater Woods (Excerpt)

By Mary Oliver

To live in this world

you must be able
to do three things:
to love what is mortal;
to hold it
against your bones knowing
your own life depends on it;
and, when the time comes to let it go,
to let it go.

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#### **Dear CSL: Long Distance Caregiving**

By the Caregiver Support Line

Yesterday was a really hard day! I was in an evening meeting and got 10 texts all at once from my two brothers about our dad. They live in Montreal, and I live in Kamloops.

The texts are filled with choppy bits - "It's Dad. He's had a massive stroke. Don't fly home. He was a candidate for surgery and is recovering in hospital. He should be fine. We will call you tomorrow with an update."

I'm feeling stressed about not being with my family right now and so worried about my dad. I also feel helpless being a plane ride away. Do you have any strategies to help me care from afar?

Stuck and worried in Kamloops



#### Dear Stuck and Worried in Kamloops,

A healthcare crisis is stressful when you are apart from your loved ones. No wonder you feel stressed and helpless! Distance caregiving can be quite the ride—guilt for not doing enough or for not being there, sadness in accepting the toll a disease can take, anxiety and stress about the unknown, and travelling back and forth to help. Caregiving can work across distance with key strategies including:

**Talk First, Act Later.** To start, get an assessment of the situation. Collect information, be it during a visit or over the phone. Find out what's being done by family in town, friends, and community health professionals. This will help map out a care and support plan as well as highlight gaps to fill.

**Learn Everything You Can** about the disease or disability affecting the person you are caring for. This becomes the backbone of your care and support plan

**Build a Team That Works:** Find out who is in regular contact with the person being cared for and seek their participation on the care team. This can include nearby family and friends, other family and friends who are distant but involved, neighbours, community organization and health care teams. Be clear in advance on what type of care and help is needed and assign everyone tasks best suited to their skills, interest, availability and willingness.

**Get to Know the Locals.** Build in time to research what programs and supports are available in the community. Patience and persistence are a must to navigate a health care system from afar! Friends or neighbours up the street from your care recipient can check in on them, update you on events, changes to the community and more. This knowledge can help you share ideas, information and resources with the rest of the caregiving team.

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**Communication is Key:** Life would be simpler if we were all mind-readers! Until that happens, being clear, concise and direct is the best thing. Long-distance caregivers often feel left out of decisions or get information second hand. Agreeing on a communication plan is a best practice. It can help prevent family feuds and allow everyone to know and understand the options. For example, one family member might be designated as the primary contact person. Consider using an online calendar and task system that are widely available now so that your care team can access and receive updates.

**Know Your Limit, Care Within It:** Caregiving doesn't happen in isolation of life and it's easy to get absorbed in your role as family caregiver. You may want to define the limits of what you are prepared and able to do. This will help you see more clearly what is needed and realistic for you to provide. At FCBC, our Caregiver Support Line and coaching staff can support you with making a plan for your well-being. We also have a helpful flipbook called *Caregiver Support Plan: Making it Personal* to help you identify your needs as a caregiver and build a customized plan for yourself and the person you are caring for.

You can find many helpful resources in our Caregiver Learning Centre, under the Resource and Education heading in the Caregiver Learning Centre. Look under Listen, Read and Watch to find content in the sections on Long-Distance Caregiving.

If you are new to caregiving, a great place to start is our flipbook - *New to Caregiving: How to Prepare and What You Need to Know. The Importance of Healthy Boundaries in Caregiving* is a great read on how to care within boundaries.

#### 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 <u>www.familycaregiversbc.ca/get-help/other-community-supports</u> to find details on caregiver support groups in your community.

Support groups can be found in the following B.C. communities:

Abbotsford	Gabriola Island		
Burnaby	East Kootenay		
Campbell River	West Kootenay		
Chilliwack	Kamloops		
Comox Valley	Keremeos		
Coquitlam	Lake Country		
Cowichan Valley	Langley		
Cranbrook	Maple Ridge		
Delta	Mayne Island		
	Nanaimo		

Nelson
North Vancouver
Oliver
Pender Island
Penticton
Pitt Meadows
Port Alberni
Port Coquitlam
Princeton

**Prince George** 

Richmond
Salt Spring Island
Sidney
Smithers
Summerland
Surrey
Terrace
Vancouver
Victoria

#### **Caring from Afar: A Caregiver Story**

By Karla Wilson, Communications Lead, FCBC

In 2003, I moved to Vancouver Island. I had grown up in Toronto and spent four years living and working in Australia after my University graduation. I visited my family twice each year in Ontario, and happily welcomed family members to my home.

My father had died of kidney cancer in 2000, leaving my mother alone in our family home. At the time, my sister and her husband lived nearby, and my brother lived downtown. Mom filled the void of my father's loss with her two grandchildren and visited Victoria at least once each year.

In 2010, my daughter was born. Mom came for her birth and stayed for a month after. She helped with cooking, cleaning, copious amounts of baby-snuggling, and ensured I was getting enough rest. It was at this time that I started noticing the subtle changes in her. She had lost confidence in driving and removed herself regularly from social situations. None of this alarmed me. It was only afterwards that I could point to this time as the start of her disease.

In 2013, she was diagnosed with mild cognitive impairment, likely due to Alzheimer's.

Once, Mom got mixed up and forgot to pick me up from the airport in Toronto. On another trip, I helped to dispose of her car after her driver's license was revoked by her family doctor. The visits where Mom baked and cooked for us came to an end. She became most comfortable in her own living room, sitting in her leather La-Z-Boy recliner. One year, as I laced up her runners in a shoe store, I saw our role reversals with clarity.

Long-distance caregiving comes with an inherent level of guilt. Being 4,000+ kilometers away has many drawbacks, but I tried to find a silver lining in my role. I began to carve out my role in a joint caregiving effort. As a long-distance caregiver, I was able see Mom's decline more clearly than my siblings, who were still in Ontario.

When the Covid-19 pandemic hit, I managed one annual visit back to Toronto. I continued to see my mother's cognitive decline, and my siblings and I re-evaluated her needs. We instituted Meals on Wheels daily lunch delivery, regular grocery deliveries, and mail was re-routed to my sister's home. Speaking to Mom's neighbours and implementing a communal set of eyes on her and her home relieved some of our worry.

In January 2022, Mom's physical health dropped suddenly. At the point where my sister and I hadn't been able to reach her by phone for days, we acted. My sister and aunt visited Mom within a day of one another and I booked a flight to Toronto that same week. I set up appointments from Victoria to interview home care service providers and navigated Ontario's healthcare system from afar to understand what services were available. It was the first time Mom was amenable to receiving any help, which was monumental.

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#### **Caring from Afar**

#### Continued from Page 8

Two days before Mom's new personal support worker was scheduled to arrive for her visit, my sister phoned me and said she wanted to care for Mom herself. I helped with Mom's transition to my sister's house, none of us knowing this might become the new normal. After a number of medical appointments and home visits by community services, we learned that Mom's dementia had moved from the mild to moderate phase.

In the moment my sister decided to move Mom in with her, she became one of our country's estimated 7.8 million family caregivers. As a mother herself raising two busy teenagers, she and her husband became a member of the sandwich generation also caring for an aging parent.

I call. My husband calls. My daughter and I make video calls. I've made photo books of the family. I send printed photos. I write letters. I send cards and gifts on special occasions. I have been back to Ontario three times in one calendar year, and I am peacefully resolved in knowing we won't take family vacations for years to come. Still, no matter how much I do or plan to do, it will never seem enough.

My sister and I always said that a crisis would be what removed Mom from our family home – a house in the Toronto suburbs filled with childhood memories of joyful Christmas mornings, Easter egg hunts, countless birthday celebrations, and the regular day-to-day flurry of family activity. But, through crisis we are often able to see a different way forward. It's a new way of being, and it's always only 'for now'.

I am a long-distance caregiver. My job is to ensure my sister and her family are supported – and to support my mom as her disease progresses. What I've learned, through this journey, is that through Mom's grace, kindness, and caring, she has raised children who aren't only just willing, but who want to care for her – who find it a privilege to do so, even from 4,000 kilometres away.

#### **Resources:**

Karla Wilson's long-distance caregiving experience was recently featured in the Spring/Summer issue of <u>Dementia Connections</u> magazine (Pages 23-25)

Alzheimer Society of BC https://alzheimer.ca/bc/en



#### Walking a Mile in Their Shoes: Responding With Empathy

By Victoria Lougheed

In a recent webinar presented by Dr. Michelle Lobchuk of the University of Manitoba's School of Nursing, she talked about the importance of selfreflection in empathy-driven person-centred care. Empathy is both an individual and a social act. Engaging in self-reflection is the starting point for approaching communication with empathy. Before we can reach out and understand another person, we need a good understanding of ourselves – our lived experience and past interactions. The term "cognitive empathy" refers to how well an individual can perceive and understand the emotions of another and engage that understanding in communication with them. (1) In simpler terms, it means walking a mile in someone else's shoes. Empathy plays a critical role in all human, social, and psychological interaction in all stages of life. For caregivers, it's central to the caregiving experience, as it informs the relationship between caregiver and care recipient. Maintaining empathy in our interactions with care recipients is fundamental to person-centred care.

It's easy to fall into patterns of communication that are not person-centred as we struggle with overwhelm, fatigue and burnout. Aspects of caregiving, including repetitive conversations, behaviors expressed by our care recipients, our own isolation and fatigue, can cause emotional responses or triggers. Our responses to these events can vary based on our frame of mind, and on the circumstances. Through self-reflection we can become aware of our triggers and understand how to work through them. (2)

As caregivers, we can use the **LIFE exercise** to remind ourselves to engage cognitive empathy in our interactions with loved ones.

#### **LIFE Exercise Communication Technique**

#### - Listen, Identify, Feel, Engage

Listen – focus on your care recipient with genuine interest and curiosity. Be present in that moment with no distractions. This is sometimes called "Active Listening" and is all about really paying attention, without bias, and not already forming your response while the other person is still talking.

**Identify** emotions— look to the emotions your care recipient is expressing when they try to tell you something. Are they frustrated, angry, sad, or even showing no emotions at all — these are all telling you important things about their feelings

**Feelings** – try on the care recipient's perspective. What were they feeling. What were YOU feeling while listening? Step into their shoes for a moment to try and experience the conversation from their side.

**Exchange** inferences – What is your understanding of the care recipient's feelings? Retell their story as if it's your own. What do YOU feel? This will give you insight into how your care recipient is feeling in this moment.

Using the LIFE exercise will help you step out of your own emotional state and move past negative patterns of responding to your care recipient. It can help you ensure that their voice is acknowledged as part of their care.

View the webinar here: https://bit.ly/3gVQeR6

#### Footnotes:

- 1. "The Psychology of Emotional and Cognitive Empathy" Article from Lesley University
- 2. "How to Identify and Manage Your Emotional Triggers" Raypole Nov 12, 2020 Healthline

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#### DISEASE/CONDITION SPECIFIC CAREGIVER SUPPORT

**ALS Society of BC** Here to Help (Mental Health) heretohelpbc.ca

1-800-708-3228 no area code; free; 24 hour line 310-6789 www.alsbc.ca/

**Alzheimer Society of BC Huntington British Columbia Resource Center** 

1-800-667-3742 chd.med.ubc.ca/home/hsc-resource-centre/ alzheimer.ca/bc/en

604-822-7195 First Link Dementia Helpline 1-800-936-6033

**MS Society of Canada** 

**BC Brain Injury Association** mssociety.ca 1-800-268-7582

brainstreams.ca 604-984-1212

**British Columbia Schizophrenia Society** parkinson.bc.ca 1-800-668-3330

**Parkinson Society B.C.** 

1-888-888-0029

Fraser Health

**Stroke Recovery Association of BC BC Cancer Agency** bccancer.bc.ca/contact strokerecoverybc.ca 1-888-313-3377

#### PROVINCIAL SUPPORT RESOURCES

**Crisis Centre BC** 1-800-SUICIDE **Anti Fraud Centre** 1-800-784-2433

antifraudcentre.ca 1-888-495-8501 Ccisiscentre.bc.ca BC211—non-medical www.bc211.ca

**Family Caregivers of British Columbia BC Association of Community Response Networks** familycaregiversbc.ca

info@bccrns.ca bccrns.ca Caregiver Support Line (toll free) 1-877-520-3267

**B.C. Health Authority General Inquiry Lines** Find Support BC (findsupportbc.com) 1-855-412-2121

Interior Health 250-388-2273 or 250-980-1400 **First Nations Health Authority** 

fnha.ca 1-866-913-0033 Island Health 1-888-533-2273 Vancouver Coastal Health 604-263-7377

HealthLinkBC—medical—healthlinkbc.ca Northern Health 250-565-7317 Call 811 any time 24/7 to speak with a nurse.

**B.C.** Ministry of Health 1-844-880-PAIN Pain BC gov.bc.ca/health

info@nidus.ca

familycaregiversbc.ca

www.seniorsfirstbc.ca

painbc.ca 1-844-880-7246 Visit www.healthlinkbc.ca/healthtopics and

enter "caregiver in the search field **Nidus Personal Planning Resource Centre** • Visit www.patientsaspartners.ca for the free

nidus.ca

self-management activities

**B.C. Palliative Care Benefits** 

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www.health.gov.bc.ca/pharme/outgoing/ palliatibe.html

**Seniors First** 

SAIL—Seniors Abuse and Information Line

Vancouver Metro 604-437-1940 1-877-952-3181 **BC Seniors Guide** 

Toll Free 1-800-437-1940 gov.bc.ca/seniors-guide

PDF Available in English, Chinese, French, Korean, **UBC Pharmacists Clinic** 604-827-2584 Vietnamese, Punjabi and Farsi, Hard copy available pharmsci.ubc.ca/pharmacists-clinic

## 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

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