

CAREGIVER CONNECTION



Family Caregivers
of British Columbia

— Let us help —

30 YEARS

SUMMER 2020

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CAREGIVING DURING COVID-19

Kate Landreth, Education and Learning Lead,
Family Caregivers of BC

Caregivers' voices and experiences are a central element to our educational resources and support offerings at FCBC. We listen to understand the needs of caregivers with the intention to provide relevant information and topics that will assist and support the wellbeing of caregivers. Your voice truly does matter!

We are grateful for the caregivers who shared their experiences, insight and wisdom on our podcast, *Caregivers Out Loud*. If you haven't yet listened, you can find all four episodes here: www.familycaregiversbc.ca/podcast/

We have also connected with caregivers during COVID-19 to share their experiences with the

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

Caregiver Support Line

1-877-520-3267

www.familycaregiversbc.ca

community. These caregivers openly shared the changes in their role, which include, but are not limited to, reduced respite, increased care time (which meant reduced working hours for employed caregivers) and additional worry and stress to ensure the health and safety of their care recipient.

From the conversations we have had with caregivers, one thread remains similar, the caregiving role does not stop. “We have to adapt so that COVID-19 doesn’t affect our lives in a dangerous way,” said a caregiver in Vancouver, BC. This full-time caregiver provides care to her 69-year old mother, who has severe dementia. Her mother lives with her full-time and she does not have the luxury of self-isolating; her mother needs 24/7 care and as an employed caregiver she requires both home support and private care to ensure that her mother is well taken care of and is safe. Additional caution and protocols within her home are in place to ensure that anyone entering is wearing a mask, gloves and changing into clean and sanitized clothes.

“No one prepares you for caregiving,” she says, and “being a full-time employed caregiver, respite is my only option to avoid burnout.” The topic of burnout is a common one with caregiving. And this caregiver relayed something quite impactful on the topic of COVID-19 and caregiving: “I am not worried as much about getting COVID, as I am about getting other diseases that are associated with burnout.” Our conversation identified the challenges and struggles of navigating the system and advocating on behalf of her mother, and she also highlighted the deep personal shifts and changes she has had through her caregiving role. She is grateful for her resiliency skills and work-ethic, as they have ultimately allowed her to keep her mother living with her. She used words like “honour” and “opportunity” to describe her caregiving role. “It is a gift to give love and support to my mother...our relationship wasn’t

always close, but this has allowed us to heal areas of our relationship.” COVID-19 cannot “stop the machine of caregiving” and she is making educated decisions on how to care for her mother in times of uncertainty.

Our next caregiver graciously shared her COVID-19 caregiving experience, while also bringing awareness to her sister’s experience with Alzheimer’s Disease using a popular app called TikTok. If you are like us and new to TikTok, it is a social media platform for creating and sharing short videos.

Jean cares for her 59-year old sister who has early onset Alzheimer’s Disease and in the past year she moved herself and her sister in with her parents. She wanted to ensure a sense of safety, security and community for her sister, while also being there when needed to support her aging parents. Alzheimer Disease does not run in their family and it took time to make a diagnosis. Her sister is a vibrant, successful, competent and creative individual, who started to have cognitive decline with symptoms such as misplacing things, confusion and forgetfulness.

Jean has shifted her life to be a caregiver, including adjusting her working schedule. She expressed gratitude for the place that she lives in beautiful BC and the ability to isolate together. During COVID-19, her sister’s regular routine and supports outside of the home stopped, which has caused some frustration and boredom. To limit the amount of people entering and exiting the home, Jean does the grocery shopping and errands. Her sister has also been able to have virtual medical appointments, which has supported them during this time. Jean’s caregiving role has remained the same, but there is an additional layer of worry and anxiety when considering protection and safety. “I am incredibly proud of my sister, and our relationship. Caregiving has a very sweet side, aside from the anxiety, grief and stress of it all,” Jean explained. And you can see this

EDITOR'S NOTE

Kate Landreth, Education and Learning Lead, Family Caregivers of BC



I am very happy and honoured to be part of the Family Caregivers of BC (FCBC) Team, contributing to the plentiful educational resources for unpaid caregivers of family and friends. I have had the good fortune of learning from and working alongside Janet McLean as she transitions into her new role as Evaluation and Quality Improvement Lead and will be overseeing the production of the beloved Caregiver Connection Newsletter, amongst other educational resources such as our Caregivers Out Loud podcast and webinars.

Shortly after I started my role with FCBC, the world changed rapidly with the onset of COVID-19. This drastic change in how we live and care for others has highlighted our degree of interconnectedness, while we remain unique and diverse. The reality is that we are not all having the exact same experiences during this time, nor have we had the same challenges. We have different capacities and temperaments, and even within the same household we may be meeting this moment in completely different ways. Through our

Caregiver Support Line we have heard from many caregivers: caregivers new to their role as a result of COVID-19 who have many questions about the supports available, as well as longstanding caregivers who need emotional support during self-isolation. It has highlighted the importance of FCBC's pillars of Caregiver Education and Caregiver Support and the need to bring caregivers' voices and experiences to the forefront. FCBC continues to advocate for caregiver support and caregiving awareness. We have extended the hours of our toll-free Caregiver Support Line, which is available Monday to Friday from 8:30 a.m. to 7:00 p.m. and have added virtual and telephone service options in this time of physical distancing.

As we wrote, collected and curated articles for the Summer Caregiver Connection, our intention was to share varying caregiving perspectives and experiences along with, relevant supports to consider during isolation.

sweet and caring side in their creative and informative videos (on TikTok). The videos highlight her sister and her journey with Alzheimer's Disease. These videos have gotten thousands of views and hundreds of heartwarming comments that have lifted their spirits during their time in self-isolation. Jean shared, "I wanted to capture these moments to help my sister remember certain times of her life." You can find these videos here: www.tiktok.com/@jfcthisusernamestress

We set out to capture caregiving stories during the unique time of COVID-19 and what became apparent is that, while the act of caregiving never stops, it does adapt. Through our connection and communication with caregivers we are continually inspired by their compassion, perspective and resiliency.

CAREGIVER CONNECTION

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Family Caregivers of BC

1-877-520-3267

www.familycaregiversbc.ca

FCBC VIRTUAL CAREGIVER GROUPS

Lycia Rodrigues, FCBC Greater Victoria
Caregiver Support Lead & Stacey Dawes,
FCBC Provincial Caregiver Engagement Lead

Over 1.1 million people provide unpaid care for family members and friends in British Columbia*.

During this pandemic, more strain and isolation has impacted the support and wellbeing of caregivers throughout our province. Family Caregivers of BC is a provincial organization and we are here to serve and support you during these uncertain times. We offer both local (Greater Victoria) and Provincial Caregiver Support groups.

FCBC offers a weekly virtual support group for caregivers throughout the province. These meetings are led by trained facilitators who are committed to offering you a space that is non-judgemental, encouraging, and understanding. The provincial caregiver support group is meeting Wednesdays 2:00-3:30 p.m. PDT (re-occurring meeting), preregistration is required for each meeting. To get details about registration please email staceydawes@familycaregiversbc.ca.

Our local FCBC caregiver support group staff and volunteers feel that this time of uncertainty and anxiety has one clear message: We're all in this together. It is essential that caregivers in Greater Victoria have peer support available and can continue to connect and share emotional and practical support. Our courageous and committed volunteers took on the new challenge of utilizing Zoom technology to facilitate our new Virtual Caregiver Café in Greater Victoria. We plan to temporarily replace our face-to-face monthly support group with this Virtual Café giving us all the chance to connect and support each other through these weekly



meetings. Each volunteer has graciously donated their time to facilitate and welcome their regular participants to this Virtual Café. The local caregiver support group is meeting Thursdays 2:00-3:30 p.m. PDT (re-occurring weekly meeting). There is limited space and pre-registration is required. To register email cgsupport@familycaregiversbc.ca or contact our Family Caregiver Support Line at 1-877-520-3267 Ext 1.

This is our maiden voyage with virtual support groups, and we are thrilled that new and existing participants continue to join us by phone and online via Zoom. Thank you for joining us during these unusual times, and we look forward to connecting with you virtually!

*Population Estimates BC, 2019, Retrieved from www2.gov.bc.ca/gov/content/data/statistics/people-population-community/population/population-estimates. Population in BC 15+ multiplied by 25% as per Stats Canada GSS 2018 finding re: percentage of caregivers in Canada www150.statcan.gc.ca/n1/daily-quotidien/200108/dq200108a-eng.htm

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 help keep you resilient.

1. I am satisfied with my overall personal health.

Yes No

2. I have the skills and information I need in order to give the required care.

Yes No

3. I maintain regular contact with family and friends and make time to spend with them.

Yes No

4. 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

5. I am able to communicate effectively with the person I am caring for, as well as others involved in their care.

Yes No

6. I am aware of community resources available to help support me in my caregiver role.

Yes No

7. I am aware of caregiver support groups (locally or online) and/or have a supportive network where I can share my challenges and successes.

Yes No

8. I make use of respite options available and take breaks from my caregiving responsibilities.

Yes No

9. 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 I can.

Yes No

10. I know how to navigate the healthcare system and who to ask if, and when I need help.

Yes No

What's your score?

Give yourself one point for every "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 would be helpful.

5-7 Points: You understand the importance of self-care, but you're 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 the resources that exist to help you) or internal (you have trouble asking for and receiving support). Sharing the care is essential to finding enough time and energy for yourself. Choose one statement you responded "No" 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 ten statements as a guide to creating a self-care plan, and start with learning more about the caregiver support resources available to guide you. It will be important for you to identify resources you're not currently using in your social circle, such as family, friends, acquaintances and neighbours, to share the care and create some much-needed space for addressing your own wellbeing.

Find resources to help you on Family Caregivers of BC's website:
www.familycaregiversbc.ca

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

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United Way
Greater Victoria

COVID-19 AND ELECTRONIC WITNESSING OF WILLS

Amy-Alexandra Jaworsky, Lawyer and Notary
with Randall & Murrell

The COVID-19 pandemic has been a challenging and unprecedented time for everyone in the world. One need only tune to a news channel for heartbreaking stories about seniors and others in care facilities. Physical distancing measures, quarantines and fear of accidental transmission of the virus to immuno-compromised people means that the ability of our elders and others to access programs or support is curtailed or cancelled. Family caregivers, used to being facilitators and getting things done for those in their care, may feel helpless in the face of the pandemic restrictions.

Another consequence of the restrictions on those who are under quarantine or who must stay in isolation is the ability to make a Will. The gravity of the pandemic has caused many to make sure their affairs are in order in case the unthinkable happens but those under quarantine have an additional hurdle to overcome when they need a Will prepared. In British Columbia, a Will requires signatures on a Will to be witnessed. But what if the will maker is under quarantine or infected with the virus? What then? Not only are two witnesses required to be present at the same time with the will maker in order for the document to be valid, but the witnesses cannot be people who take a benefit under the Will. Finding two witnesses who are unrelated but still willing to put themselves at risk in this way is a big ask.

Fortunately, one solution arrived on May 19, 2020 when the BC government issued a ministerial order that permits a will-maker to sign a Will through the use of video conference technology. This order permits a will maker and his or her witnesses to be

“electronically present”. In order for a Will witnessed by video conferencing to be valid, one of the witnesses must be a lawyer or a notary public and the Will must include a special statement that it was electronically witnessed. The will maker and the witnesses must be able to hear and see each other just like they could if they were physically present and each person signs their own copy of the Will. The ministerial order applies to Wills made on or after May 19, 2020 but it is only in effect while the state of emergency exists in British Columbia.

The BC government also issued a similar ministerial order in relation to Powers of Attorney and Representation Agreements. A Power of Attorney is a document that gives power over your financial affairs to your trusted representative. A Representation Agreement is a document that gives power over your health and personal care matters to your trusted representative. A copy of the ministerial order for Wills can be located here: www.bclaws.ca/civix/document/id/mo/mo/2020_m161 and the ministerial order for Powers of Attorney and Representation Agreements is located here: www.bclaws.ca/civix/document/id/mo/mo/2020_m162

The ability to carry out remote witnessing of a Will is a welcome step forward during these unprecedented times and gives back some control and perhaps a little peace of mind to those who have been so greatly impacted by COVID-19.

**Reach Amy-Alexandra Jaworsky at
250-382-9282 or amy@viclawfirm.ca**

REFRAMING SELF-CARE: PERSPECTIVE IS EVERYTHING

Elizabeth Bishop, Caregiver Support Program Coordinator with North Shore Community Resources

Self-care is a buzzword right now, but what does self-care really mean? For many busy caregivers, self-care is an afterthought. However, with high rates of caregiver burnout, taking care of your mental and physical health is so very important.

COVID-19 has brought many challenges and uncertainties in relation to caregiving, but it also presents an opportunity to pause and tune into your internal compass and listen to what you need.

Being vs. Doing

For many caregivers, 'self-care' is just one more thing to add to an already long list. Self-care is rooted in self-awareness. It is recognizing you are a human being, not a human doing. Meaningful self-care is a posture you take, allowing you to listen and respond to your personal needs on a holistic level. The cornerstone of self-care is self-compassion, which emphasizes kindness to self and recognizing your human experience. Active and genuine self-care integrates all areas of life, whether you are at home, at work, or caring for other people, you keep your own well-being at the center of your experience.

Self-Care Does Not Mean Selfish

Wise author and coach, Iyanla Vanzant uses the term 'self-ful' to help us reframe what it means to take care of ourselves on every level. Self-care is a holistic practice and it means caring not only for our physical health, but also our emotional, mental, spiritual, financial, and social health as well. When you

care for yourself from a 'self-ful' perspective, you honour the needs of your mind and body. It also invites you to nurture and care for yourself through emotional rough waters with a gentle and encouraging inner attitude. Research shows that self-compassion people tend to be more caring and supportive in relationships and more compassionate and forging towards others (Neff, K. and Germer, C, 2018).

You Don't Need a Reason

A common misunderstanding people have of self-care is that it may appear selfish (which evokes feelings of guilt). Caregivers often hear that self-care is important because "you can't pour from an empty vessel" and are reminded that you must "put on your oxygen mask first before we help others." Often, we soothe our apprehension by affirming that this time for ourselves will enable us to *give more* to others.

Consider caring for yourself just because you... well care for yourself! It is an expression of self-love and a demonstration of self-compassion. You do not have to feel bad in order to feel better or even good. When you feel well and nurtured from within, you will find that there is more of you that can overflow naturally to the people in your life in ways that are not depleting and draining.

During Zoom meetings and Face time calls, choose wisely how you spend and share your precious energy. Balance your need for quiet and solitude with your desire for connection and socializing. Self-care is checking in with yourself to understand what you need during these uncertain times.

May the mystery of this time unfold for you in miraculous ways.

CONNECTING VIRTUALLY WITH FRIENDS AND FAMILY

Niki Andresen, Product Development Coordinator with Ability411

Virtual connection has never been as important as it is right now. British Columbia has seen an expansion of virtual service delivery in response to COVID-19.

Unfortunately, this rapid expansion makes it difficult for even the most tech savvy among us to keep up!

At Ability411 we answer questions and provide practical information about technologies, tools and equipment that increase independence and well-being for BC seniors, and support their families and care teams. Lately, we have received questions from seniors and their caregivers across BC about the challenges of virtual connection.

Video calling has presented a wonderful opportunity to check in remotely with family members – whether they are down the street or in another time zone. To keep things simple and easy with video calling try to meet your loved one where they are, virtually. If they

have a Facebook account that they log into regularly, then try using Facebook Messenger's integrated video calling.

Consider the device they use too. If they are a tablet user, Google Duo is a great option for Android tablets since it relies on the Google account already associated with that device. Computer-users don't need to install new software to use Skype, or Zoom – both are now available to use in the browser, just like visiting a website.

A big barrier for seniors with less digital experience is accounts and passwords. For seniors who have no accounts online whatsoever there are still options, such as Linkello. This website lets you make a link that you can then share with the senior - send it in an email or even relay it to them over the phone. The link is active for 24 hours in the free version and the senior can join just by visiting the link and typing in their name.

Video calling doesn't just have to be with family. You can easily meet with a doctor without having to line up at the clinic. This is a particularly good option for getting a prescription refill or a referral. These services are covered by MSP, so they will require a BC Personal Health Number. Like with clinics, there are many options including Access Virtual, Babylon by Telus Health and WELL Health Virtual Clinic+.

Medical appointments are not the only service available virtually. Shopping for groceries has been a challenge for many seniors with physical frailties, and now it's become a real challenge for seniors who are practicing physical distancing. There are plenty of options to order fresh food to be delivered to your doorstep – and not just for people in urban areas. While the services may be delayed due to the increased volume, the



planning and scheduling of meals can be an absolute time saver – particularly in comparison to visiting a grocery store.

Many British Columbians are already aware of the larger stores offering delivery, such as Save-On-Foods and Walmart. There are also delivery services that will shop on your behalf at a store or pick up an online order and deliver it to you. Meal kits, such as HelloFresh, can be a fun option to explore, as they provide you with the correct quantities of each

ingredient to complete a recipe that comes with your order. Vancouver-based Fresh Prep provides ingredients already prepared, a great option for those who don't want to spend as much time in the kitchen.

You can read more about video calling, and grocery delivery on Ability411.ca

Do you have more questions about technology to support caregiving? Ask us a question online at www.ability411.ca/ask-new-question

OPINION

WHO WOULD BE A CAREGIVER?

Patricia Jean Smith

In Canada one in four people will suffer a stroke in their lifetime. My husband, Ron, had his stroke seven and a half years ago. Initially, he was completely paralyzed on his right side and came home from hospital in a wheelchair. For many years I resisted calling myself a caregiver. I consciously rejected the term, although I never thought to examine why. After discovering the Family Caregivers of BC website this spring, I was intrigued to learn that not identifying one's self as a caregiver is a common experience, although I didn't learn why this is so.

In my own case I suspect that being as committed as I was to full recovery, I expected my once familiar world would some day be restored, that Ron would heal completely, and I would no longer be a caregiver. My condition was temporary. At some future point I would return to my writing career and to being Ron's wife, Nicole and Owen's mother, Iain and Jen's mother-in-law, and Flora, Lochlan and Anja's grandmother. All these identities I readily embraced.

Admitting to being a caregiver meant facing up to a reality I wasn't prepared to accept.

It was a new reality that meant Ron might be permanently handicapped and in continual need of my assistance.

I also rebelled against the reductionism I felt the term caregiver implied. It suggested to me that I now belonged to the legion of people who were no longer masters of their own destiny but slaves to the needs of others. Somehow identifying as a caregiver felt wrong to me. It said to me that the scope of my life had contracted. Whereas, in many ways, it had grown immeasurably.

Perhaps I also believed the word oversimplified Ron's and my new situation. If I were a care-giver did that make Ron a care-taker? After all, he continued to write and edit, as he had done before, without my assistance. He still had a life independent of me. The first time I heard the term "care recipient" was on the FCBC website. Weren't Ron and I more like comrades in arms, both

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JOIN A CAREGIVER SUPPORT GROUP IN YOUR COMMUNITY

Due to COVID-19 please check with the individual support group to know how they are providing support at this time

Visit our website to find details on caregiver support groups in your community:

www.familycaregiversbc.ca/family-caregiver-support-groups

Toll-free: 1-877-520-3267

Support groups can be found in the following BC communities:

Burnaby
Campbell River
Comox Valley
Coquitlam

Cowichan Valley
Delta
Gabriola Island
East Kootenay Area
Kamloops
Keremeos
Langley
Maple Ridge

Mayne Island
Nanaimo
North Vancouver
Oliver
Pender Island
Penticton
Port Alberni
Port Coquitlam

Port Moody
Princeton
Prince George
Richmond
Salt Spring Island
Sidney
Smithers
Summerland

Surrey
Vancouver
Victoria (See Pg. 4 for Virtual Support Groups)

facing a challenge? Today I am inclined to think that one of the reasons for my previous reluctance to identify as a caregiver was the fact that the work family caregivers do is unpaid or poorly paid. We live in a society where nurturing and giving isn't appreciated. I hope that living through a pandemic will change this, that we will understand where our true value lies, and that the society we inhabit will embrace the universality of 'giving care'.

"Be Kind Be Calm Be Safe"

**Dr. Bonnie Henry, Provincial Health Officer
for British Columbia**

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

Here to Help (for Mental Health)

310-6789 (no area code; free available 24 hours a day)

Huntington's Society of BC

BC Resource Center: 604-822-7195

MS Society of Canada (BC)

1-800-268-7582

Parkinson Society BC

1-800-668-3330

Stroke Recovery Association of BC

1-888-313-3377

PROVINCIAL RESOURCES

Anti Fraud Centre

www.antifraudcentre.ca

1-888-495-8501

BC 211 - non-medical

www.bc211.ca

BC Health Authority General Enquiry Lines

- Fraser Health 1-855-412-2121
- Interior Health 250-980-1400
- Island Health 250-388-2273 or 1-888-533-2273
- Vancouver Coastal Health 604-263-7377
- Northern Health 250-565-7317

BC Ministry of Health

www.gov.bc.ca/health

Visit www.healthlinkbc.ca/healthtopics and put in the search term "Caregiver".

Visit www.patientsaspartners.ca for the free self-management activities offered through Patients as Partners

BC Palliative Care Benefits

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

BC Seniors Guide

www.gov.bc.ca/seniors-guide

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

Hard copy available in English, Chinese, French, Punjabi

1-877- 952-3181

Crisis Centre BC

crisiscentre.bc.ca/contact-us

1-800-SUICIDE (1-800-784-2433)

Family Caregivers of British Columbia

www.familycaregiversbc.ca

Caregiver Support Line: 1-877-520-3267

Find Support BC

findsupportbc.com

HealthLink BC - medical

www.healthlinkbc.ca

Call 811 anytime 24/7 to speak to a nurse.

Here to Help - mental health

www.heretohelp.bc.ca

Pain BC

www.painbc.ca

The Nidus Personal Planning Resource Centre

www.nidus.ca

email: info@nidus.ca

Seniors First

www.seniorsfirstbc.ca

SAIL - Seniors Abuse & Information Line

Vancouver - Metro 604-437-1940

Toll Free: 1-866-437-1940 (8am-8pm daily)

Language Interpretation (9am-4pm M-F)

www.seniorsfirstbc.ca

UBC Pharmacists Clinic

www.pharmsci.ubc.ca/pharmacists-clinic

WE CAN HELP RIGHT NOW



BC Caregiver Support Line 1-877-520-3267

Toll-free, available Mon-Fri, 8:30am-4pm



info@familycaregiversbc.ca



www.familycaregiversbc.ca

Help build a stronger family caregiver community & make the future brighter

Donate

Support our mission and vision of the future where family caregivers are valued, supported and included as partners in care, or donate to today's caregiver support and education programs.

Call toll-free at 1-877-520-3267 or donate online at Canada Helps

Family Caregivers Society of British Columbia is a registered charity (#12981 7771 RR0001) A charitable tax receipt will be issued for donations of \$20 or more.

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