

CAREGIVER CONNECTION



Family Caregivers
of British Columbia

— Let us help —

30 YEARS

SPRING 2021

VOLUME 35 ISSUE 2



Family and Friend Caregivers on the Front Lines of COVID-19

Are Caregivers Missing Out?

By Janet McLean, Evaluation and Quality Improvement Lead
with Family Caregivers of BC

In December 2020, Family Caregivers of BC (FCBC) conducted a province-wide survey of unpaid family/friend caregivers. The goal of the survey was to understand how COVID-19 has impacted caregivers in BC, no matter where they live, where their care recipient lives or if their care recipient is currently receiving publicly subsidized services. Over 1,000 caregivers completed the survey, and the data is painting a picture about the challenges caregivers are facing - both before and during the pandemic.

Not surprisingly, COVID-19 has emphasized the essential role caregivers play in helping the people they care for live their best lives. On top of radical changes in their own personal circumstances such as employment, finances and managing the risk of COVID-19, caregivers reported being challenged around quickly adapting carefully crafted routines and/or

Continued on page 2

In this issue

- Findings from our COVID-19 Impact Survey
- The Power of Many
- How Setting Intentions Can Support Your Caregiving Direction and Focus
- What You Need to Know About Powers of Attorney
- A Caregiver's Story

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

creating new routines they hadn't anticipated. All of this contributed to over 50% of caregivers reporting a decrease in their mental health and 40% reporting a decrease in their physical health. To read more you can find our Survey Highlights Release on our website www.familycaregiversbc.ca

One observation emerging from the survey data is how many caregivers – through lack of awareness and/or information – report they are not benefiting from available supports. And what we know from evidence on caregiving, caregivers who are well supported have a much greater chance of sustaining their role.

Community Supports

Here are examples of the kind of caregiving we heard about through our survey:

85% of caregivers were already caregiving when COVID-19 arrived:

- ~50% reported they have been caregiving for up to five years, **a third caregiving 6+ years**
- ~50% reported they are providing 11+ hours of care per week of care, **20% provide 40+ hours**
- Over **40% of caregivers reported providing more care because of COVID-19**, 40% exceeding 11 additional hours per week

The level of caregiving represented by the survey data is significant. Yet, the caregivers reporting this level of care were also those most likely to report they are not taking advantage of supports. For example, three quarters reported their care recipients were not receiving publicly subsidized home support services through their Health Authorities. This is not a bad thing in and of itself but if a caregiver is providing a high level of support over long periods of time, it becomes more and more likely their ability to continue caregiving will decrease until they become a risk to themselves and their care recipient. The same caregivers are often unaware of other caregiver supports available through provincial organizations like BC211 and community-based non-profits. Many new programs and services have launched because of COVID-19. If you aren't sure what services might be available to help with your caregiving, call our **BC Caregiver Support Line @ 1-877-520-3267**. Our staff will listen to understand your situation and refer you to

support groups and other provincial and community resources that may be able to provide much needed assistance.

Financial Breaks

Many of the caregivers who responded to our survey also reported they are not taking advantage of available caregiver benefits through the federal government. While it is true that many of these benefits depend on being employed or having an annual income that will benefit from tax credits, not taking advantage of them if they are applicable is a missed opportunity. One quarter of caregivers reported experiencing financial hardship as a result of caregiving during COVID-19, with 50% reporting they employed private services to assist with medical and personal care and spent their own funds on Personal Protective Equipment and food.

Roughly 70% of caregivers reported not receiving any federal benefits to assist with caregiving.

- Only 6% reported taking advantage of Caregiver Tax Credits which are not dependent on employment
- Only 3% of caregivers reported receiving the Canada Caregiver Recovery Benefit - a federal program developed to assist employed caregivers with challenges caused by COVID-19

If you are wondering if there might be financial breaks you are unaware of, FCBC created a financial guide that is posted on our website: www.familycaregiversbc.ca/wp-content/uploads/2021/02/Guide-to-Financial-Assistance-January-2021.pdf.

We also have an up-to-date listing of information about financial benefits available because of COVID-19: www.familycaregiversbc.ca/community-resources/covid-19-virus.

Caregivers are often so busy they don't feel they have time to reach out for support. However, this might mean they are missing out on supports that could help them. For support on your unique situation please contact the CRA General Inquiries Line: 1-800-959-8281 or discuss what tax credits and benefits you may be eligible for with your accountant. You can also call BC Caregiver Support Line (1-877-520-3267) or visit our website www.familycaregiversbc.ca.

Editor's Note

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



According to the common adage, March is supposed to go in like a lion and out like a lamb, but springtime rarely arrives without a bite. It takes time to warm up, and often, so do we. But when it does, there is something so promising about the beautiful buds of pink cherry blossoms and lingering daylight. It signifies a sign of renewal and starting fresh – brighter, warmer days are ahead. This is a perfect time to purge things from your home, workspace, or inbox, or perhaps it may be time to let go of feelings or thoughts that are not supporting you. You may also try something new, like setting a personal intention that you can nurture like a seedling, integrating 5 more minutes of movement a day, or engaging in a forgotten hobby. Small, yet simple additions may ignite hope and vibrancy into your life.

May is Family Caregivers Month in BC and we are excited to offer learning, webinars and caregiver connection opportunities that will support and celebrate caregivers! We are also thrilled to launch new and insightful podcast episodes from **Caregivers Out Loud**. The episodes in this season touch on topics of caregiver loss and grief, self-awareness and personal growth, and spiritual connections and grounding. We hear from caregivers how the peaks and valleys become more manageable when we broaden our perspective, become curious and connect to personal values. Please follow us on our social media platforms (Facebook, Instagram, and Twitter) or subscribe and read our bi-weekly Enews for the details of our upcoming Caregiver Aware month!

This spring issue of Caregiver Connection has a variety of information and articles that will provide perspective, hope, and support at this time. Janet McLean shares highlights from our **COVID-19 Impact Survey**, with identified areas where caregivers may be missing out on supports. Barb MacLean, our Executive Director, provides insight into our important health systems collaboration work, ensuring caregivers are partners in care. Our legal piece titled **Did You Know?** shines springtime light on tricky areas of Powers of Attorney, Wills, and Representation Agreements. To relate to your experience as a caregiver, we share **A Caregiver's Story of Perspective, Patience and Timing** – growing to understand that two opposing truths can exist simultaneously. Finally, to support your intention setting, we have included some tips on how to set intentions and how doing so can support your caregiving direction and focus.

I will close with sharing this quote that I have displayed in my own workspace, reminding me to appreciate what I can each day:

“Listen to your life. See it for the fathomless mystery it is. In the boredom and pain of it, no less than in the excitement and gladness: touch, taste, smell your way to the holy and hidden heart of it, because in the last analysis all moments are key moments, and life itself is grace.” || Frederick Buechner

From my heart to yours,
Kate Landreth

**We gratefully
acknowledge
our donors and
funding partners**



The Power of Many

By Barb MacLean, Executive Director, Family Caregivers of BC

This is a tribute to each and every family and friend caregiver, the beautiful, giving human beings who care, who love and who do their best.

Our whole team at FCBC wants you to know that we have heard your voices, your impactful stories and that we are grateful to be part of your world.

The pandemic, amidst so much pain and suffering, has revealed a new appreciation for the family caregiver role. By taking it away – think Long Term Care – it proved to fuel dialogue and put the wheels in motion for improved policies on family presence. It added new caregivers, unexpectedly thrown into the role, creating a greater awareness among families, employers, and communities. It also motivated people to speak out and speak up.

What we are doing at FCBC

You might be most familiar with our Caregiver Support and Education Programs – for example, the BC Caregiver Support Line, support groups, webinars, podcasts and online tools and resources. What you might not know much about is our health systems collaboration work, a strategic priority that hasn't been as visible. It is where we dive into our health system, looking for opportunities to shift thinking, action and culture so that caregivers are included as partners in care.

We do this in many ways, with staff and amazing volunteers, including media interviews, focus groups, surveys, research participants, presentations, articles and committees. These

are examples of the ways that we share the caregiver lens. Our long-term project, Caregiver RX, captures the three key changes we seek in our health system: to identify, support/refer and include caregivers as partners in care. Our goal is to embed these changes in processes and structures within our health system for enduring, positive change. Each step taken to integrate, and respect caregivers brings us closer to caregiver friendly health care.

Partners in care

This is where the rubber hits the road. Sadly, the story of Long-Term Care revealed a huge gap in understanding the value of caregivers as essential – but that is now poised for change as the world speaks loudly and we mobilize to shift both policy and culture. Feeling more hopeful, we see the shift to including both patients and caregivers in health transformation, like PCN – Primary Care Network development.

We would like you to know that you are part of a large, caregiver community. If you are inclined, join our Caregiver Engagement Program – to share your voice, your way. If you are feeling a little lonely, know that you are part of our family, the Caregiver Community. We are here for you.



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

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.

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: www.familycaregiversbc.ca

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

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

How Setting Intentions Can Support Your Caregiving Direction and Focus



By Wendy Johnstone, Provincial Program Consultant and Gerontologist with Family Caregivers of BC

We hear and validate the stories of caregivers all across BC. Caregiving offers many rewards, however, at times and currently, it can feel and be really challenging. It asks a lot of you. Our conversations with caregivers lead to a range of concerns some of the merging themes are:

- I am caring for someone 24/7 and I find myself feeling rattled, impatient (even when I know it's normal), not finding time for a break.
- I am battling my own chronic illness while caring for my adult daughter with physical limitations and depression.
- I used to see my mom every day in assisted living and now I can't. I have been consumed with listening to the news and unsure on how to re-adjust to this new state of living.
- I am trying to balance my work demands with family life and we are all trapped in the same household!

Why set an intention?

- It can be a way of coaching or supporting yourself, finding a piece of personal safety.
- Having a personal mantra or little supportive reminders helps to nurture and support yourself.
- It can aid you while caring for another person, but ultimately support you in caring for yourself.
- Helps clarify what is most important for the day or in a moment.
- It gives you permission and time to step back for a moment; to check in with yourself or to consider how you want to show up before taking on an interaction or task.
- It encourages and activates self-awareness - take a moment to pause and step back and observe your actions, attitudes, or emotions.
- It can keep you from getting swept away in a pool of the negative nellys or behaviors; and helps us move to self-compassion, reflection, and self-care.

How to find direction and focus

- Setting an intention can help you avoid getting stuck in the challenge or situation, and it also supports you in remembering what is important to you.
- Focusing on an intention allows you to meet a circumstance or behaviour with more understanding, perspective, empathy, or patience.
- Setting an intention helps to focus and calm your mind, it allows you to stay grounded when the world around you is chaotic or uncertain (think balance work and family at home).

- An example of an intention could be to take a pause from media for the morning or focus on conscious breathing when your mind gets fixed on negative thoughts.

How to set an intention

- Setting an intention is personal to you, which means you get to decide if it's a word, sentence or phrase that means something to you currently (it does not need to be profound- short, sweet and simple is key).
- There is no wrong way to set an intention. The aim is to consider what is important to you right now or something that you are aiming to cultivate (this is different than making a goal).
- You do not need to share this with anyone, it can be an internal mantra or safe place just for you.
- Practice daily, it helps with consistency, but if you forget one day no worries, just start again!
- For some caregivers, we have heard that taking 5 minutes first thing in the morning seems to be the best time.
- Write it in a journal, put it on a sticky note on your mirror, text a trusted friend and ask them to check in during the day, repeat your personal mantra, meditate with it as a focal point for 5-minutes.
- For some caregivers, taking 5-minutes at the end of day to check in helps give personal feedback. What was a win for today? What did I learn today? Would I do anything different tomorrow? (Insert a healthy dose of self-compassion!).

Intention Practice



Your brain doesn't distinguish between whether you're facing a stressful situation right now or imagining it happening. Your brain produces stress hormones (like adrenalin and cortisol) when you feel stressed in a stressful situation, but it also produces them when you imagine a stressful situation. Spun in a positive way, you can positively influence your mood and vibration with your thoughts- give it a try!

Create an intention that resonates with you. Pick and choose words that makes sense to you.

Consider a feeling-based intention for the day.

I aim to feel:

This looks like:

This sounds like:

My body feels like:

Take 5-10 cycles of slow breaths to notice your body, your breath, and your intention.

Did You Know?

By Amy-Alexandra Jaworsky

Power of Attorney

Notice required! If you change or revoke your enduring power of attorney, you must give written notice to the persons you appointed as your attorney(s) for the change or revocation to be effective.

POA terminated! If a person becomes a “patient” under the Patients Property Act (for example, if an adult child applies to the court to be appointed the guardian of the affairs of a parent who has lost capacity) a Power of Attorney previously granted by the adult is terminated.

Sharing information! Only you, the Public Guardian and Trustee or the court can require the person you appointed as your attorney to explain how they have handled your finances. If you want other family members to be able to access information about how the attorney is dealing with your finances, another option is to make this clear in your power of attorney document.

Wills

Access without probate? Having a Will is useful, even if you have very modest assets. With a Will in hand and depending on your assets and how much money is in your bank account, a financial institution may permit your executor to access your funds after you pass away without obtaining a grant of probate from the court but if you do not have a Will, then the financial institution does not know who has authority to deal with your assets.

Tax implications! If you transferred your home into joint names with another person who does not live in the home and then you pass away, when your executor gets your tax returns done, your estate may not be able to claim a capital gains exemption for the whole home for the period of time the home was held in joint ownership. If your home increased in

value significantly during that time period, the transfer may have unintended negative tax consequences.

No gift! If you give a gift to someone in your Will and that person is also a witness to your Will or the spouse of a witness, then the gift to that person is void unless your Will says differently.

Representation Agreements

Who makes decisions? If you do not want your spouse or child to make health care decisions for you when you are not capable then you can appoint a trusted person who will have the authority to make those decisions by preparing a representation agreement. If you do not appoint someone, then provincial legislation ranks temporary decision makers for health care in a certain order (ie spouse, adult child, parent and then others) and health care providers will make reasonable efforts to choose the first person who qualifies and is available.

Spouse’s authority ends! If you and your spouse separate, the spouse’s authority in your representation agreement ends unless your agreement says differently.

No authority! You cannot appoint someone to be your representative if they are paid to provide care to you or if they are an employee of a facility through which you receive personal care or health care (unless that person also happens to be your spouse or child).

Your specific situation may impact the examples given in this article. Consult a professional if you have any questions.

Amy-Alexandra Jaworsky of Island Law Office is a Victoria lawyer practicing in the areas of wills, probate and residential real estate.

amy@islandlawoffice.ca / 250.858.0344.

A Caregiver's Story of Perspective, Patience and Timing

By BKN, A Family Caregiver

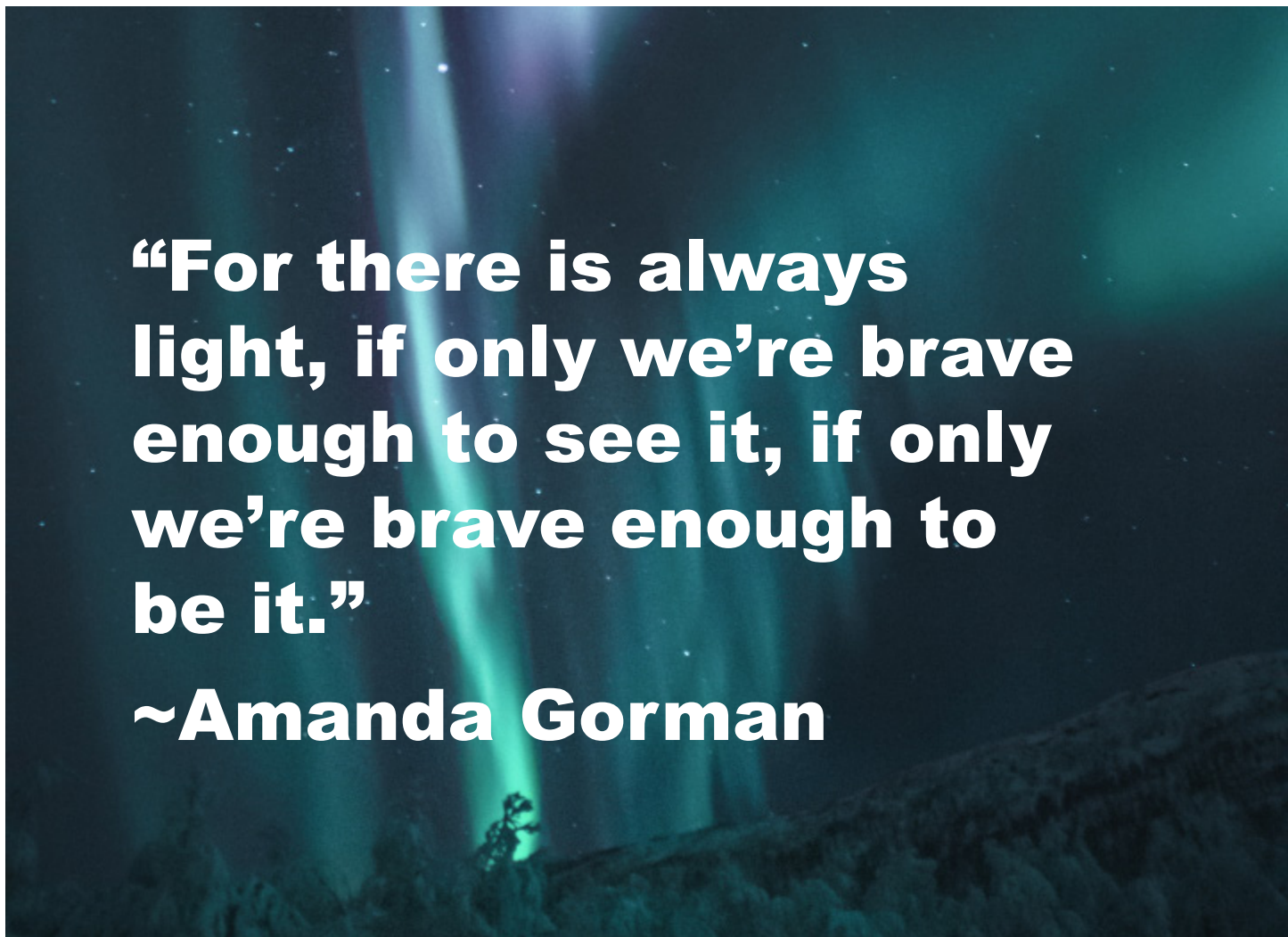
Me at the window: "It's nice and sunny today."

My husband looks and says: "Bullsh*t! That's fog."

In 2014, my husband had a hemorrhagic stroke. Today, mostly recovered, he is physically able and retains important skills such as speech, walking, eating, and self-hygiene. However, his mild dementia includes confusion, vision deficits, comprehension, and problem-solving. He resists or is unable to absorb new information or guidance. In frustration, he becomes belligerent and

argumentative. At times like these, the least said the better. I back away until he's calmer or appears receptive (e.g., asks a question).

My truth: the nice weather is obvious. Also true is his fog, because to him the glaring light appears like a blanket of fog. So, while he cannot be forced to see my perspective, I can learn to see his. He may be receptive if I approach an important issue in another way, on another day. He has taught me that harmonious communication is often about observation, perspective, patience, and timing.



**“For there is always
light, if only we’re brave
enough to see it, if only
we’re brave enough to
be it.”**

~Amanda Gorman

Join a Community Caregiver Support Group

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

Visit www.familycaregiversbc.ca/family-caregiver-support-groups/ to find details on caregiver support groups in your community.



Support groups can be found in the following BC communities:

Burnaby
Campbell River
Comox Valley
Coquitlam
Cowichan Valley
Cranbrook
Delta
Gabriola Island
East Kootenay

West Kootenay
Keremeos
Lake Country
Langley
Maple Ridge
Mayne Island
Nanaimo
North Vancouver
Oliver
Pender Island
Penticton
Port Alberni

Port Coquitlam
Princeton
Prince George
Richmond
Salt Spring Island
Sidney
Smithers
Summerland
Surrey
Vancouver
Victoria

Family Caregivers of BC Presents

Season 2 of our Podcast! Listen Today!

By sharing the stories of caregivers, we bring you perspective and connection, and ensure that you have support and balance from diverse caregivers and people who support caregivers.

www.familycaregiversbc.ca/podcast



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 hr)

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 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/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

First Nations Health Authority
www.fnha.ca Toll-free: 1-866-913-0033

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 | 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-7pm



info@familycaregiversbc.ca



www.familycaregiversbc.ca



**Family Caregivers
of British Columbia**

— Let us help —

30 YEARS



Do you want to keep receiving this?

In the past, you provided Family Caregivers of BC with your mailing address in order to receive this quarterly newsletter. If you no longer want to receive this paper copy, please contact Administration at 250-384-0408 Ext. 2 or email info@familycaregiversbc.ca



Trying to go paperless? Save a tree

Subscribe to receive the quarterly Caregiver Connection & more by email
www.familycaregiversbc.ca/newsletter-subscription

Family Caregivers Society of British Columbia
#6-3318 Oak Street
Victoria, BC V8X 1R1

Publications Mail
Agreement #40040515