

CAREGIVER CONNECTION



Family Caregivers
of British Columbia

Let us help

30 YEARS

SPRING 2020

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CELEBRATING 30 YEARS

Barb MacLean, Executive Director,
Family Caregivers of BC

Picture this: you're embarking on a marathon in a new country, starting off quite alone and uncertain of what lies ahead. You cross rivers, climb hills and pass through lush valleys, gaining confidence and then, wham! The desert appears, your water supply runs low, the sun and wind batter you relentlessly. You question your ability to continue; your pace slows as you conserve energy. "How do I carry on?" you ask, feeling alone and discouraged. Shapes appear on the horizon and a village emerges. Water is shared, shelter is offered, and a warm hand touches your weary shoulder. You rest in the company of others who have also run many miles. Both your body and mind are nourished, and with deep resolve, you slip battered feet into well-worn

Continued on page 2

In this issue

- FCBC celebrates 30 years!
- New national caregiving statistics
- The new national caregiver distress indicator
- An update on our podcast
- Generations of caregiving
- Are your elderly parents stubborn or misunderstood?

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

shoes. The fire in you is lit again and you know you'll carry on.

This story is about caregiving. It's drawn from thousands of stories we've been lucky enough to be part of, as caregivers have found their way to our programs and services. We have witnessed how important emotional support and education are for people to tap into, promoting their own deep and enduring resilience.

This is also much like our story, which began more than 30 years ago, when one person's insights about the need to support family caregivers melded into a common vision held by many. Being the first organization of its kind in Canada, we forged ahead into unknown territory where caregivers were voiceless and unseen. There were many, many obstacles and – most importantly – there were many, many incredible people who threw their time, ideas, money, determination, and compassion into overcoming each and every obstacle.

In celebrating 30 years we are really celebrating people with passion, grit, resolve,

caring, determination, and love. As an organization “for caregivers, by caregivers” we honour the legacy of those who have walked – or run – a thousand miles in caregiving shoes to help us build for the future.

Looking forward, we are energized by progress within health care to identify, support, and include caregivers as partners in care. Check out our first-in-Canada social prescribing approach – the “Caregiver RX” at familycaregiversbc.ca/webinars-for-health-care-providers. Remember that our Caregiver Support Line is there for you. You are not alone. Stay tuned for a new approach to education – you asked for it – as we launch our first Caregivers Out Loud podcast season (find more on page 7). We have expanded our May Caregiver Week to a whole month of awareness building with our partners across Canada with #CaregiverAware2020.

The fire is going strong. On behalf of our amazing and talented staff, board and volunteers, Happy 30th!

FAMILY & FRIEND CAREGIVER SUPPORT PROGRAM GRANTS: FCBC'S ROLE

Whitney McMillan, Provincial Project Lead,
Family Caregivers of BC

Over the decades, FCBC has welcomed collaboration opportunities – they are key to our evolution, growth, and outreach. One of our latest and most exciting collaborations, in partnership with the United Way and the Community-Based Seniors Services' Leadership Council, is our co-backbone role supporting a new funding initiative bringing local support to family and friend caregivers across BC. Funded by the Province of BC, the Integrated Community-Based Programs for Older Adults with Higher Needs grant projects will support local non-profit organizations to start new or expand existing Caregiver Support Programs in 17 urban, rural and

remote areas of BC. Our FCBC co-backbone role aims to provide these Family & Friend Caregiver Support Programs with caregiver support expertise, education opportunities, and health care connections to demonstrate the positive impact community-based services can have on the wellbeing of family and friend caregivers. Over the next 2.5 years, the FCBC team will provide ongoing behind-the-scenes support to these grant programs – collaborating to achieve shared outcomes and continuing to build caregiver support capacity in BC.

Email whitneymcmillan@familycaregiversbc.ca for more information about the Higher Needs grants and/or specific Family & Friend Caregiver Support Programs.

EDITOR'S NOTE

Janet McLean, Education and Engagement Lead, Family Caregivers of BC

May is Family Caregiver Month in BC and this issue of the Caregiver Connection is dedicated to celebration. During the month of May, FCBC will be marking every day with items of interest to caregivers through our website and posts on social media. We will also be holding events in Greater Victoria to celebrate 30 years of supporting caregivers through our local programs and services. And while much has changed in 30 years, the basics of caregiver support remain the same as pointed out in our cover article by Executive Director, Barb MacLean. By helping caregivers understand they are not alone, providing a variety of supports to meet a diversity of needs and keeping abreast of shifts in caregiving demands, we can meet the needs of caregiving sprints and marathons.

What *is* changing is the shift in public and health system awareness about the valuable contribution of family/friend caregivers to our society and this is hugely encouraging. For example, the Statistics Canada General Social Survey on caregiving helps inform our understanding regarding the magnitude of caregiving across Canada and in BC. Our article on page 4 talks about the latest survey conducted in 2018 and how it will help us

shape our programming and services. Another sign of the increasing awareness is the work that has been done by the Canadian Institute of Health Information to develop a national Caregiver Distress Indicator. FCBC staff and a volunteer family caregiver representative were involved in the development of the indicator and it is hoped it will highlight the impact of providing supports to caregivers to enhance their ability to manage ongoing demands. Read more about the indicator on page 6.

As always, we have included a few articles that touch on common caregiving themes. Whether it is about preparing to care from the perspective of a young caregiver (page 6-7), to common frustrations about communicating with aging care recipients, we hope there is something you will find helpful. And finally, we hope you will subscribe to our upcoming podcast “Caregivers Out Loud” launching April 14th! Tune in to hear the advice of caregivers through the voices of caregivers. Learn more on page 7.

As always, thanks for caring.

Janet



CAREGIVER CONNECTION

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1-877-520-3267

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NEW NATIONAL CAREGIVING STATISTICS

Janet McLean, Education and Engagement Lead, Family Caregivers of BC

Every six years, Statistics Canada conducts a survey of unpaid family/friend caregivers in Canada. The most recent survey was conducted in 2018 and work is currently underway to publish a series of reports that will interpret the findings. Initial data has been released and one report has been published. These are available on the Stats Can website¹

For the purposes of the survey, caregivers are defined as people 15+ years who provide unpaid help or care to a family member or friend with a long-term health condition, a physical or mental disability or problems related to aging. 2018 survey results indicate that one in every four Canadians over the age of 15 is a caregiver. This is down slightly from the 28% proportion found in 2012 but we would caution against concluding that caregiving is declining. To the contrary, the growth in our aging population combined with smaller family sizes would suggest the intensity of caregiving concentrated in certain age groups is increasing. For example, there has been a 5% increase in the proportion of caregivers caring for spouses and this group of caregivers invests the highest number of hours per week caregiving - an average of 14. Of note is the overall statistic that in 2018 64% of caregivers spend <10 hours caregiving per week – a decrease of 10% compared to 74% in 2012 and 21% spend >20 hours per week caregiving. This starts to tell a story about the increasing intensity of caregiving for an aging population.

Another key focus of the new statistics findings re: support received by caregivers, is data was collected re: social and financial support received based on a number of

variables. It draws conclusions about the magnitude of unmet needs and impact on caregiver well-being:

- **30% of caregivers who received support for their caregiving duties said there was another type of support they would have liked**, primarily financial, government assistance or tax credits (68%).
- **39% of caregivers said they would have liked more information or advice.**
- **38% of caregivers caring for spouses/partners reported they had unmet support needs** compared to 20% of those caring for grandparents, friends, neighbours, and coworkers.
- Unmet care needs were linked to lower life satisfaction, more daily stress and worse self-reported mental health.

At Family Caregivers of BC, the release of new national statistics provides us with a valuable backdrop against which to compare our own experience serving caregivers throughout British Columbia. We are keen to learn about national trends in who is caring for who, length and intensity of caregiving episodes and information that confirms or refutes trends we see in our population. Such trends include increases in the proportion of caregivers under 45 years, caregivers who are sandwiched between caring for parents and children and caregivers who are employed. This type of information helps us gauge the shifting needs of caregiver population “segments” reflected in their unique circumstances. We do our best to respond to differentiated needs through our programs and services. If you have any suggestions or feedback please don't hesitate to let us know: familycaregiversbc.ca/contact-us/

1. www150.statcan.gc.ca/n1/daily-quotidien/200108/dq200108a-eng.htm?HPA=1

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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ACKNOWLEDGE OUR
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CAREGIVER DISTRESS A NATIONAL PRIORITY

Raquel Betini (in consultation with Janet McLean, a family caregiver advisor for the indicator Expert Advisory Group)

What is Caregiver Distress?

Unpaid caregivers provide essential care that contributes to the well-being of the person they are caring for while also supporting the health system. However, the family member or friend who is in the caregiving role can experience distress. For instance, the caregiver may have to cope with the sudden onset of a disease or decline in health of the individual they are caring for. An increase in caregiving responsibilities can have a major impact on daily routines leaving family members and friends who are providing care distressed. Sometimes caregivers are even unable to continue in their caregiver role due to their own health problems, fatigue, and the ongoing need to juggle multiple responsibilities such as full time work and parenthood.

A new Caregiver Distress indicator is in development by the Canadian Institute for Health Information (CIHI). This indicator is being developed through consultations with stakeholders, measurement experts and the public (including family/friend caregivers), as well as a literature review on the subject. A staff member of Family Caregivers of BC also participated in the indicator's Expert Advisory Group along with a volunteer caregiver representative. This indicator will measure provincial and territorial rates of caregiver distress among unpaid caregivers of individuals who have been receiving publicly-funded home care services for longer than 60 days. The Caregiver Distress indicator will help to measure distress in a systematic

and comparable way. The indicator will be released in May on the CIHI Your Health System web-site and updated each year.

Caregiver distress: A national priority

Improving access to home and community care services is a priority for federal, provincial and territorial governments. In 2018, they agreed to work collectively to measure access to services in home and community care as part of a Common Statement of Principles on Shared Health Priorities.

The Caregiver Distress indicator is one of six indicators chosen for measuring access to home and community care services. Examples of another indicator to be released at the same time is "New long-term care residents who potentially could have been cared for at home". Others, such as "Wait times for home care" and "Home care helped the recipient stay at home" are also being developed but will be released in future.

Why is this indicator important for caregivers?

The Caregiver Distress indicator will help to recognize the contributions and challenges of unpaid caregivers as health care partners, as well as the need to evaluate the impact of caregiving on caregiver wellbeing. Annual indicator results will provide comparable rates of caregiver distress that can be used by provinces and territories to facilitate 1) initiatives aimed at reducing caregiver distress; 2) learning from each other's policies; and 3) tracking changes in the caregiver distress indicator over time.

Looking to the future

Access to home care services helps to support caregivers, enabling people receiving home care to stay home longer - whether it is

ongoing caregiving responsibilities or helping an individual move from the hospital to home. Without home care services caregivers are more likely to experience distress.

With the release of this indicator in May 2020 comes the potential to bring positive changes for accessing the right amount and right type of home care that will benefit caregivers and

those they care for.

You can see the results for this and other home and community care indicators at the CIHI YHS InBrief webpage (<https://www.cihi.ca/en/your-health-system-in-brief>). To stay informed about the public release of this SHP Caregiver Distress indicator, please email: media@cihi.ca.

CAREGIVERS OUT LOUD: ARE YOU LISTENING?

Adapted from article by Kim Davis

Family Caregivers of BC is very excited to introduce a new education platform for caregivers. We're launching our free podcast, Caregivers Out Loud!

Host, Jodie McDonald is a therapist specializing in boundary-setting, self-care and education for caregivers. Tune in to hear insightful and authentic conversations with caregivers about their joys, trials and self-discoveries during our first, four-episode season.

Waiting in doctor's offices, commuting to appointments, or taking a much-needed moment for yourself? Listen in!

What's a podcast?

Similar to a regular radio or TV show, podcasts are a series of audio episodes you can listen to online or download onto your preferred device (like your iPad or smartphone). Many are free and can be accessed through a number of apps like Apple Podcasts, Stitcher, iHeartRadio, and Spotify.



Listen at familycaregiversbc.ca/podcast

You can also find our podcast at:

- Apple Podcasts
- Spotify
- Stitcher
- Deezer
- Pocket Casts
- Podcast Addict

Please share your feedback and requests

familycaregiversbc.ca/contact



GENERATIONS OF CAREGIVING

Hope Tagesen – Communications Lead,
Family Caregivers of BC

It's been just over three years since my grandmother passed away. When my grandmother's husband died, she moved near us which allowed us to help her. She didn't need much assistance at the time but I realize now it helped prepare us for what was to come. When she was 82 she had a bad fall. My mom and I were supposed to go and see her that day but decided to have a girl's lunch instead. That night when my mom phoned as she did several times a day, no one answered. She was alarmed and went to my grandmother's house to find her on the floor where she could not get up as she had broken her shoulder. We were racked with guilt. I try to remind myself we couldn't possibly be with her every second of every day, but I am still hit with pangs of guilt years later.

The fall was the turning point for my grandmother. During her recovery she needed help with housework and bathing. My mom and I did all of this for her but it began to be too much. My grandmother could no longer take care of her yard and on top of regular household chores it was more than the three of us could manage. So we moved her into an apartment, where we helped her clean and took her to appointments. She was fairly capable but her eyesight wasn't great and her mobility was becoming limited so she needed our help more and more. We were happy to do it but it took my mom away from her own family.

When my grandmother passed away, it was a shock. Even though she had needed our care she was in pretty good mental and physical health. My mom has still not recovered and I expect she never will. During the period following my grandmother's death, the

matriarch of our family and a formidable force, the family unit went through a long period of adjustment. No one knew what our new roles were or how to find them.



As time wore on, we adjusted and found a new normal but no one prepares you for the family shift and settling after a crucial family member passes. Like we prepare for a real earthquake, preparing for the emotional quake and aftershocks are important.

My mother and I are very close, just as she was with her mom. The experience with my grandmother has made me more conscious of what the future holds for me as a caregiver - the inevitable movement of life that I cannot stop. I miss my grandmother terribly and will always be grateful I was able to help care for her, and in caring for her, have the knowledge and experience to be able to help care for my mom as she grows older and needs me. I don't know when that will be but I know with certainty it will happen. Experiencing

caregiving for a loved one as a young person was hard and eye opening and can be overwhelming especially if it is a long journey. There are many young caregivers in BC caring for parents, siblings, relatives and friends and

that number is growing. If you are a young caregiver needing support, please visit familycaregiversbc.ca for resources or call the caregiver support line toll-free at 1-877-520-3267. You are not alone.

STUBBORN ELDERLY PARENTS OR MISUNDERSTOOD?

Joseph Jones – California Mobility,
californiamobility.com

As an adult child of senior parents, you will probably at some point need to help them make important decisions. While you only want what's best for your parents, they may have different ideas about what is best for them. This can lead to misunderstandings that can cause disagreements and put a strain on your relationship.

A study published in *The Journals of Gerontology: Series B* in cooperation with Rowan University and Penn State University, found that there is a discrepancy between what behaviors adult children of seniors and their parents view as stubborn. According to this study, 66% of seniors and more than 77% of their adult children reported that the behavior of the senior parents showed stubbornness at least some of the time, and one of the main causes of this discrepancy may be a mismatch of goals that can lead to misunderstandings.

For example, driving is one instance where these misunderstandings often occur. Most senior parents want to continue to drive as long as possible, but eventually driving may become unsafe. Seniors may have the goal of controlling where they go and when, and their adult children may have the goal of protecting their parents by reducing the chance for accidents. While you may think you have stubborn elderly parents, they may just have



different goals than you do.

We asked several experts to share their thoughts on avoiding misunderstandings when seniors and their adult children have different points of view about important issues. Below are some tips they shared with us.

Encourage Their Independence Whenever Possible

Pamela D. Wilson, caregiving expert, advocate, and speaker with The Caring Generation, says “Adult children may define parents as stubborn when the aging parent is trying to maintain as much independence as possible. In many care situations, adult children become impatient with aging parents who have slowed down . . . Supporting [the] independence of an aging parent is the best course of action in the long run.”

Be Patient and Mindful in Your Approach

According to Fritzi Gros-Daillon, MS, CAPS, CSA, SHSS, with Age Safe America, if you

Continued on page 10



JOIN A CAREGIVER SUPPORT GROUP IN YOUR COMMUNITY

Caregiver support groups are growing across British Columbia! This is great news. But it also means we've run out of space in our newsletter to print all of the details.

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

**[www.familycaregiversbc.ca/
family-caregiver-support-groups](http://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



think your senior parents are being stubborn, “Then you need to take a mindful approach and acknowledge their concerns. Patience, fortitude, and grace are the qualities that may bring the best results.”

Choose Your Battles Wisely

“Pick your battles. Let small things slide,” says Bonnie Friedman, author of *Hospital Warrior: How to Get the Best Care for Your Loved One*. “Save your energy for talking about important issues, such as those that involve their personal safety or financial well-being.”

Consult Authority Figures

According to Anastasia Blaszczyk, family

caregiver, president and founder of Aging Parents Management, says “When dealing with stubborn parents, the problem is most likely the messenger. Bring in third parties to help you get through the situation. Stubborn parents may be more receptive to the opinions of people of authority – doctors, attorneys, social workers, etc.”

If you are your parents’ caregiver, it’s especially important to listen to them and try to understand their perspectives. These tips can provide a great place to start if you don’t all see eye-to-eye.

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 for 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.

Please make cheques payable to:

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Volunteer

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