

Caregiver Distress - We Can Help

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

On August 29th, BC’s Seniors Advocate released her second report on caregiver distress “Caregivers in Distress – A Growing Problem”. As part of the report preparation, the Seniors Advocate consulted Family Caregivers of BC about our experience in supporting caregivers. We confirmed that calls to our province-wide Caregiver Support Line are increasing and many caregivers are coping with increasingly complex caregiving situations. We are spending more time on each call and many are referred to our 1:1 Caregiver Coaching service to receive in-depth support. We are noticing that more caregivers are distressed which translates into feelings of depression, confusion, overwhelm, and uncertainty about how they can continue. This matters because most caregivers want to continue supporting their care recipients to live at home in their communities as long as possible. The challenge is caregiver distress can have a significant negative effect on caregiver’s health. A recent Ontario report on caregiving¹ sites studies that show these negative effects can range from back problems, migraines, stomach ulcers, hormonal changes, anxiety and depression to early death.

Here is a snapshot of the Seniors Advocate’s key findings about the growth of caregiver distress in BC:

- 95% of Home Support clients in BC have caregivers



Janet McLean addresses caregiver distress on The National, August 30 2017.

- The percentage of these caregivers who are in distress is 31%, a 7% increase since the first report “Caregivers in Distress – More Respite Needed” was published in 2015
- This equates to roughly 1,000 caregivers, a 14% increase in actual numbers out of a total of roughly 31,000 caregivers
- Three main factors account for caregiver distress: the complexity of care recipient needs, the relationship and co-residing status of the caregiver and the amount of care delivered
- Care recipient conditions that contribute significantly to caregiver distress are: cognitive impairment (mild impairment doubles the risk, moderate to severe

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Let us help. Call the BC Caregiver Support Line 1 877 520 3267

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impairment triples); dementia (increases risk by 25%); presence of behavioural and psychological symptoms of dementia (increases risk by 75%); depression (doubles the risk)

- Caregivers who live with their care recipient are 40% more likely to become distressed and if you are a spouse this increases to 80%
- The more hours of caregiving you provide, the higher the potential for distress

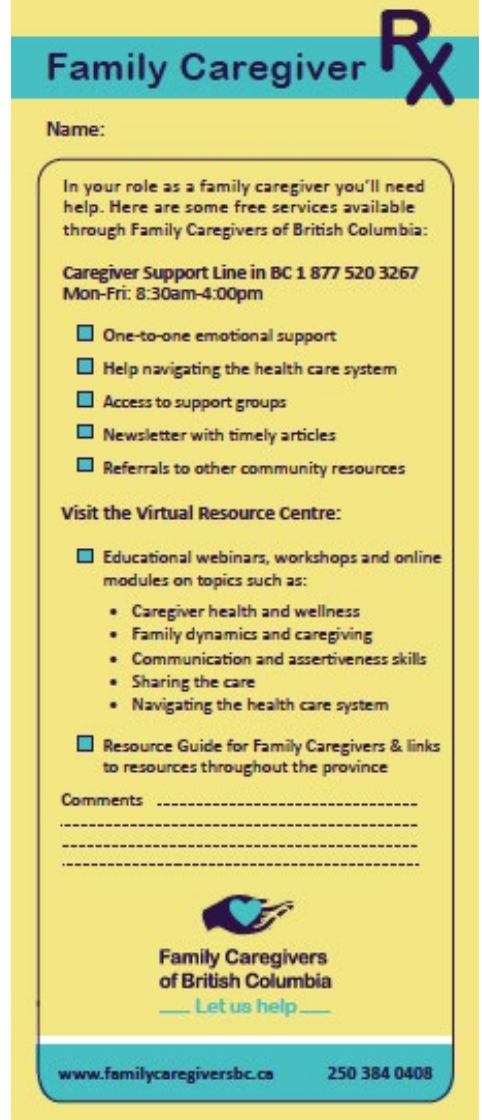
The Seniors Advocate recommends additional system resources that would help caregivers by providing a break from caregiving duties – commonly referred to as respite. The three provincial respite programs she examined are Adult Day Programs, Home Support and Residential Care Respite. As well, she recommends system changes in the way health professionals work with caregivers. For example:

- The province should work with Family Caregivers of BC to develop a standardized format for health professionals to provide all home support clients and their caregivers with information on accessing local caregiving supports and resources in their community
- Consideration should be given to developing a caregiver referral process that would allow health care providers to refer caregivers who consent directly to community caregiver support organizations

We are encouraged by these recommendations. The Caregiver Prescription featured at right is a product of a collaboration with physicians and health authority community health services staff. This new tool is now a significant source of referrals to our services. In addition, we are currently working with community based organizations across the province to help them understand how they can play a big role in supporting caregivers. Our goal is to make sure that no one has to care alone and that health care professionals have an easy way to refer caregivers to support long before they become distressed.

To read the Seniors Advocate’s full report, go to <https://www.seniorsadvocatebc.ca/osa-reports/caregivers-in-distress-a-growing-problem-2/>

¹ Health Quality Ontario, The Reality of Caregiving. 2016



Family Caregiver Rx

Name: _____

In your role as a family caregiver you'll need help. Here are some free services available through Family Caregivers of British Columbia:


Caregiver Support Line in BC 1 877 520 3267
Mon-Fri: 8:30am-4:00pm

- One-to-one emotional support
- Help navigating the health care system
- Access to support groups
- Newsletter with timely articles
- Referrals to other community resources

Visit the Virtual Resource Centre:

- Educational webinars, workshops and online modules on topics such as:
 - Caregiver health and wellness
 - Family dynamics and caregiving
 - Communication and assertiveness skills
 - Sharing the care
 - Navigating the health care system
- Resource Guide for Family Caregivers & links to resources throughout the province

Comments: _____


Family Caregivers of British Columbia
 — Let us help —

www.familycaregiversbc.ca 250 384 0408

New referral tool: Caregiver Prescription

Editor's Note

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



This issue of the Caregiver Connection is about ensuring no one cares alone. The evidence is in as outlined in the cover article about the recent Seniors Advocate’s report “Caregiver Distress – A Growing Problem”. Over 1 in 4 adults in BC are caregivers and contribute an estimated \$3.5 billion worth of care to the people they care for and our society. We couldn’t afford to pay them for this service and we certainly can’t afford to let them care without support. However, as the article on caregiver self-identification points

out, caregivers often don’t realize they are caregivers until they are well into the journey and as a result, miss out on valuable supports and assistance that could have made a huge difference.

Stay tuned for the launch of our provincial Caregiver Referral form in November. We are asking all of you to help us by identifying yourself or a caregiver you know and getting support early. Don't care alone.

-Janet

Are You Missing Out?

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

CarersUK published a report in 2016 titled “Missing Out – The Identification Challenge”. The subject of the report was the challenge of caregiver self-identification. The report found that caregivers often don’t self-identify because they relate more to their relationship with their care recipient than with their role as a caregiver. They are children, wives/husbands and friends who are providing care as part of their relationship – they don’t see themselves as caregivers. The problem with this is early identification and support of caregivers is critical to long term caregiving. The report goes on to outline how not identifying as a caregiver has resulted in caregivers missing out on valuable supports. Some of the findings include:

- The majority of caregivers took over a year to recognize their role and 24% took over 4 years
- 91% of caregivers said they missed out on financial or practical support (or both) as a result of not identifying as a caregiver
- 50% reported that missing out on support had impacted their physical health
- 78% suffered from stress and anxiety that may have been addressed
- 61% said that missing out on support had put a strain on their relationships with family and friends
- 52% believed they had missed out on financial support
- 42% reported giving up work when that might have been prevented

These findings are sobering especially in light of the growing numbers of caregivers in distress. Our cover article on BC’s Seniors Advocate’s recent report on “Caregivers in Distress – A Growing Problem” points to the personal toll caregiving can have on caregivers’ health. Are you one of the 31% of caregivers in distress identified in this report? Or perhaps you know someone who is? And what does that mean for you or that person you know? Once you have made a commitment to care there is seldom any turning back and yet the evidence is clear, risk of distress needs to be addressed.

Family Caregivers of BC is ready to help so you don't



miss out. We operate a resource centre that can be accessed from anywhere in the province by phone or computer.

**Call from anywhere in British Columbia:
Caregiver Support Line 1-877-520-3267**

- One-on-one emotional support
- Help navigating the health care system
- Referrals and information on community resources
- Caregiver coaching appointments

Visit the virtual resource centre for family caregivers at www.familycaregiversbc.ca

- Educational webinars, workshops and online modules
- Blog and helpful handouts
- Toolkit for employers for supporting family caregivers in the workplace
- Links to community resources
- An opportunity to have a voice in improving the health care system

In November, we are going to launch our provincial family caregiver referral form so that anyone will be able to refer a caregiver to us with that person’s consent so they don't miss out. We believe it is up to all of us to recognize the valuable contribution caregivers make to our society and don’t believe anyone should care alone. Take our challenge and refer a caregiver you know – or simply call us yourself.

3 Ways to get a Peaceful Sleep

By Karyn Davies, RCC, MA , Coordinator, North Shore Caregiver Support Program

Care manager. Wife extraordinaire. Cook. Social coordinator. Housecleaner. Warrior husband. Any of these might describe what your caring role looks and feels like.

When you've been running around for most of the day, managing appointments, mealtimes, and making sure things go smoothly - by the time it's evening, you might be tempted to just crash falling into bed without any wind-down time. While this is alright to do on occasion, it's really important to create a routine that allows you to relax before going to bed. A wind-down routine signals to your mind and body that it's time to stop doing and going - and to simply rest.

Nighttime routines help you:

Let go of the day, and release any physical tension caused by stressful events.

Acknowledge what was difficult today, and appreciate the small successes.

Prepare your nervous system for a restful sleep.

3 things to try:

Soak - Soak your feet in warm water, and then use your favourite lotion to give yourself a foot massage. The warm water will ease tension and help your system unwind, while the fragrance will be soothing. I enjoy using pink Himalayan salt or Epsom salts in my foot soak.

Cozy up - Make your bedroom cozy. Switch on your favourite lamp or light a candle on your bedside table.

Thankful time - Spend 1 minute reflecting on what made you sad or mad today. After acknowledging how you felt, visualize those events floating away from your body - send the negative thoughts away! Then for 3 minutes, think about what made you smile or feel uplifted. Hold the feeling of joy and thankfulness with you as you close your eyes.

Wishing you the restful sleep you truly deserve!

What do YOU do at nighttime for self-care?

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<https://northvancaregivers.wordpress.com/>

The Dwindling: A Daughter's Caregiving Journey to the Edge of Life

By Janet Dunnett

So, what do you do when your caregiving days are finally over? That time will come, of course. Most of us are so busy treading in the white water sweeping us along that it's hard to believe there will be calm water ahead. But suddenly it appears around the bend of life, and navigating that too is part of the journey. Here's the story of my "after".

Dad died first. My feelings about that seemed uncomplicated. He died according to the expectations of the doctors who said "they wouldn't be surprised if he was gone within three months." There was sadness of course, but it was a graceful time bringing more relief than grief. By the time dad died though, Mom's struggles that had been going on for years were at a new crescendo. Fierce advocacy on

her behalf was the biggest need now. Caregiving was still full time.

Then after another year of crises piled one on the other, Mom just died. One week, her body conked out. "That's the way it goes," the doctors said. She died for all sorts of reasons and for no special reason. If her death certificate said "heart problems", the truth was, it was just "old age", but that's not a diagnosis. The busy time of funeral, inheritance sorting and the paperwork involved in not being around any more passed after a few more months. It was time to get back to what had been important a decade ago. Could I remember back that far? I floated aimlessly through the months with little writing projects here and there.

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Have you Joined Huddol Yet?

Huddol makes it easy for caregivers to share and solve everyday care challenges together. Huddol's rich social environment works to help match caregivers to the best possible sources of support, keeping them connected to their peers, experts, and a network of public and private resources. For caregivers, building their very own care community through Huddol means that they always have a network by their side every step of the way.

Family Caregivers of BC has joined the Huddol community because it is committed to seeing families through their caregiving experience.

Caregivers who want to be a part of our Huddol community can join us by visiting Huddol.com/join/selfcompassion



The Impact of Telemedicine Use on Caregivers

By Kristina Van from Broadway Clinic and Health Centre

According to a recent study done in Canada, the average caregiver spends 4.1 hours per week commuting due to caregiving commitments.¹ Commuting to a general practitioner creates unnecessary strain on caregivers when trying to access MSP covered services.

The Broadway Clinic and Health Centre is working to relieve caregivers by bridging the gap between patients to communicate through video or conference with physicians on a computer, tablet or smart phone over a secure network. This will reduce the barriers of access so that patients can consult a doctor on the day of a concern, before it becomes a serious medical situation.

"A Systematic Review of Telehealth Tools and Intervention to Support Family Caregivers" found that many caregivers believe that technology can help make caregiving more efficient and less stressful when delivering care for patients.² This could be because of the various ways technology can benefit caregivers. For example, it will make it easier to help with accompaniment to doctor appointments, as visits can be done in the home. This is especially convenient for dependents living with Alzheimer's, as behavioural symptoms can make travel to a clinic more challenging.⁴ Telemedicine will also allow patients to renew prescriptions and have it sent to a pharmacy or discuss test results and have follow up appointments with a doctor.

In addition, a study done in B.C. found that most patient-physician virtual visits were viewed to be as thorough as an in-person visit. It was discovered that 93.2% reported that their most recent visit was of high quality and 95% reported confidence in the security and privacy of their personal information.³

Use of telemedicine will allow increased and more efficient communication between caregivers and healthcare providers.

The Broadway Clinic and Health Centre offers evening appointments to accommodate caregivers working full time. This service comes at no additional cost to the family, as all medically necessary services are covered by the Medical Service Plan (MSP) for B.C. residents.

For more information please refer to our website at www.bchealthcentre.ca. We can also be reached at info@bchealthcentre.ca or at 96040 416-0271.

1. "Balancing Paid Work and Caregiving Responsibilities: A Closer Look at Family Caregivers in Canada," 2009. http://caregiversns.org/images/uploads/working_caregivers_EN.pdf
2. "A Systematic Review of Telehealth Tools and Interventions to Support Family Caregivers," December 4, 2014. http://journals.sagepub.com/doi/full/10.1177/1357633X14562734#_i14
3. "Virtual Visits and Patient-Centred Care: Results of a Patient Survey and Observational Study," May 25, 2017. <http://www.jmir.org/2017/5/e177/#ref1>
4. "Demential Care Comes Home: Patient and Caregiver Assessment via Telemedicine," February 3, 2017. <http://academic-oup-com.ezproxylibrary.ubc.ca/gerontologist/article/2967600/Dementia>

We gratefully acknowledge our donors and funding partners



Events

November 9 Webinar

Touchy Topics About Caregiving
-Joan Braun, Mediate BC

November 17 Change Day

Family Caregivers of BC is a proud partner in Change Day. Make a pledge to refer a family, friend or neighbour to Family Caregivers of BC so that no one cares alone.

November 23 Webinar

Caregiving Shouldn't Cause Injuries – SafeCare BC

Find more events at familycaregiversbc.ca/events

Caregiver Connection

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Family Caregivers of BC

1 877 520 3267

www.familycaregiversbc.ca



Caregiver Stress Test

The following test will help you become aware of your feelings and the pressures and stress you currently feel. Responses are:

1 = Seldom 2 = Sometimes 3 = Often 4 = Usually 5 = Always

_____ I find I can't get enough rest.

_____ I don't have enough time for myself.

_____ I don't have time to be with other family members besides the person I care for.

_____ I feel guilty about my situation.

_____ I don't get out much anymore.

_____ I have conflict with the person I care for.

_____ I have conflicts with other family members.

_____ I cry every day.

_____ I worry about having enough money to make ends meet.

_____ I don't feel I have enough knowledge or experience to give care as well as I'd like.

_____ My own health is not good.

If your response to two or more of these areas is "Always", "Usually" or "Often" it may be time to look for help with caring for your family member and making time to take care of yourself as well. Call Family Caregivers of BC's toll-free Caregiver Support Line at 1 877 520 3267 or visit www.familycaregiversbc.ca for more information and resources.

Building Caregiver Support in BC Communities

By Kim Davies & Lycia Rodrigues



Family caregiver support groups provide an opportunity for family caregivers to come together in a safe and supportive environment to

share their feelings and experiences. Being part of a support group can help family caregivers feel less isolated and provide the opportunity for mutual support, friendship and information sharing.

In the interest of collaborating with those who offer and facilitate these invaluable groups throughout British Columbia, the Family Caregivers of BC (FCBC) is organizing the first Support Group Facilitators Community of Practice (CoP) meeting on Thursday, November 16th from 1:30-4:30 pm.

The FCBC is looking to co-create a community of practice, as well as increase the capacity for volunteer support facilitators, by engaging in joint activities and discussions about local support groups, and helping build relationships within and between communities.

The Support Group Facilitators Community of Practice (CoP) meeting will be held at City Centre Library Surrey, as well as streamed via videoconference. Lycia Rodrigues, FCBC's Caregiver Support and Engagement

Lead, will be facilitating the event.

Originally from Brazil, Lycia has been passionate about improving the quality of life for caregivers and older adults for many years. She began her vocation as a psychologist, working with adults with chronic diseases in Brazil's public health programming context. She later furthered her interest and training by completing a Master in Social Dimensions of Health at the University of Victoria, with a focus on Gerontology.

As part of her dedication to increasing engagement and support for vulnerable adults, for the past ten years she has worked in various capacities with seniors programming, through non-profit organizations and health authorities, in the Lower Mainland and on Vancouver Island.

Given her own multicultural experience, she is also keenly interested in how cultural values and assumptions impact family caregiving. In the future, she looks forward to exploring how Family Caregivers of BC might offer support specific to these issues.

FCBC's Provincial Program for family caregivers is supported by the Ministry of Health's Patients-as-Partners Initiative, in recognition of the significant role that family caregivers play in our health care system and society. This program includes engagement and collaboration with support groups across BC.

Support Group Facilitators Community of Practice (CoP)

Thursday November 16th, 1:30pm-4:30pm

City Centre Library Surrey

10350 University Drive, Surrey, BC

In addition to the Support Group Facilitators Community of Practice (CoP) meeting, the following are free presentations and training sessions being held throughout the Lower Mainland and Southern Vancouver Island:

Community Presentation at West Shore:

Caring for our Aging Population: We're All in it Together

Thursday, October 19th, 1:30-3:00pm

Harbourside Common House, 6681 Horne Rd, Sooke

Training sessions for Caregiver Support Group Facilitators

These interactive trainings include content on family

caregiver support group facilitation and how to establish a family caregiver support group in your community.

Chilliwack, Mission, Agassiz and Harrison Hot Springs:

Wednesday, October 25th 1:30-4:30pm

Where: Evergreen Hall, 9291 Corbould Street, Chilliwack, BC

Nanaimo and Oceanside:

Wednesday, November 29nd 10:00am-2:30pm

Where: Nanaimo Family Life Association, 1070 Townsite Rd, Nanaimo, BC

Victoria, West Shore, Peninsula and Gulf Islands:

Thursday, January 18th 10:00am-2:00pm

Where: TBA

To register or for more information contact Lycia Rodrigues at lyciarodrigues@familycaregiversbc.ca 1-877-520-3267

Help is available — find a support group

Please contact local groups for exact locations and times. Find details on [our website](#).

FRASER HEALTH AREA

Abbotsford

Side by Side Caregiver and Family Support Group
6256 Mt. Lehman Rd.
Paddy: 778-982-0489 or mtlehmansidebyside@gmail.com

Burnaby

Family Caregivers Program
Burnaby Seniors Outreach Services Society
2055 Rosser Ave.
604-292-3909 or lori@bbseniors.ca
www.bsoss.org

Langley

Langley Senior Resources Society
20605 - 51B Ave., Langley
604-530-3020 or info@lsrs.ca

Surrey

Seniors Come Share Society
15008 26th Ave., Surrey
604 531-9400 ext. 202 or caregivers@comeshare.ca

Surrey & Delta

Caregivers Network of Surrey/Delta
604-686-3793
Surrey: Fleetwood Villa
16028 83rd Ave.
info@caregiversnetworksurreydelta.com

Newton: Seniors Come Share
13855 68th Ave., Surrey

Delta: Northcrest Care Centre
6771 120th St.

Delta: Kennedy Senior Recreation Center
11760 88th Ave.

North Delta

Crossroads United Church Caregivers Group
Norma: 604-591-3137 or normahenryt@shaw.ca

South Delta

Caregivers' Support Network
The Centre for Supportive Care
4631 Clarence Taylor Cres., Ladner
Laurie: 604-943-3921 or info@deltahospice.org

Tri-Cities (Coquitlam, Port Coquitlam, Port Moody)

Caregiver Support Program
Karen Tyrell: 778-789-1496
SeniorCaregiverProgram@gmail.com

Maple Ridge

Maple Ridge Caregiver Support Group
Maple Ridge Seniors Activity Centre
Vcr_fv@telus.net or text 604-889-1879

INTERIOR HEALTH AREA

Cranbrook, Creston, Fernie, Golden, Kimberley, Invermere

Caregivers Network for East Kootenay Seniors
Tobi Johnston: 1-877-489-0803 or in Cranbrook 250-489-0802
caregiversnetworkek@gmail.com
www.caregiverssupport.weebly.com

Keremeos

South Similkameen Health Centre
250-499-3020

Oliver

Sunnybank—Tea Room
250-498-5084

Penticton

Trinity Care Centre
250-770-3486

Princeton

Princeton General Hospital
250-295-4464

Summerland

Summerland Health Centre
250-404-8072

ISLAND HEALTH AREA

Covers Vancouver Island and the Gulf Islands.

Campbell River

1351 Ironwood Rd
Geri: campbellrivercaregivers@gmail.com

Chemainus

Cowichan Family Caregivers Support Society
#1 Kenneth Place, Duncan
Janis: 250-597-0886 or info@familycaregiverssupport.org

Comox Valley

Senior Peer Counselling Society
#491B – 4th St., Courtenay
250-871-5940 or seniorpeercounselling@shaw.ca
www.comoxvalleyseniorpeercounselling.com

Cowichan Valley

Cowichan Family Caregivers Support Society
#1 Kenneth Place, Duncan
250-597-0886 or info@familycaregiverssupport.org

More on next page...

Duncan

#1 Kenneth Place, Duncan
 Janis: 250-587-0886 or info@familycaregiverssupport.org
www.familycaregiverssupport.org

Gabriola Island

People for a Healthy Community (PHC) Resource Centre
 Suzette Dalmage: 250-247-7311
www.phcgabriola.org

Ladysmith

Cowichan Family Caregivers Support Society
 Janis: 250-597-0886 or info@familycaregiverssupport.org

Mayne Island

Jessica Easton: 250-539-2123 or jessica.easton@me.com

Port Alberni

Echo Centre
 Samantha: 250-723-4478 or samantha@albernihospice.ca

Quadra Island

Quadra Circle Community Connections Society
 Helen: 250-285-2255 or qcircle@outlook.com

Salt Spring Island

Saltspring Seniors Centre, Ganges
 250-537-5004 or muffetmbc@yahoo.ca

Sidney

Shoal Centre 10030 Resthaven Dr., Sidney
 250-384-0408/1-877-520-3267

Victoria

Family Caregivers of British Columbia Evening Group
 #6 – 3318 Oak St., 250-384-0408

Victoria Downtown Lunch Hour Group
 250-384-0408 or victoriacaregivers@gmail.com

First Metropolitan Caregiver Support Group
 First Metropolitan United Church
 Kyla.morgan@firstmetvictoria.com
 250-388-5188 local 226

NORTHERN HEALTH AREA**Smithers**

2nd floor of the courthouse
 Jenny deVries at 250-847-2975

VANCOUVER COASTAL HEALTH AREA**North Shore**

North Shore Community Resources
 Caregiver Support Program
 #201 - 935 Marine Dr., North Vancouver
 604-982-3320
www.nscr.bc.ca/information/caregiver

Richmond

Caregivers Drop-in Group
 Rosewood Manor, 6260 Blundell Rd.
 Eleanor 604-277-3774 or sunflower31@shaw.ca

South Vancouver Family & Friend Support Group

Caregiver Support South Vancouver Neighbourhood House
 carmenorquiola67@gmail.com
 604-453-5885/604-324-6212

Vancouver

Frog Hollow Neighbourhood House
 604-251-1225 ext 237
 gloria@froghollow.bc.ca

DISEASE-SPECIFIC FAMILY CAREGIVER GROUPS

Many of these organizations also offer support & groups for caregivers caring for someone with that condition. Contact the BC office below for information about services in your community.

ALS Society of BC

www.alsbc.ca 1-800-708-3228

Alzheimer Society of BC

www.alzheimer.ca/bc/ 1-800-667-3742
 First Link Dementia Helpline 1-800-936-6033

BC Brain Injury Association

www.brainstreams.ca 604-984-1212

British Columbia Schizophrenia Society

www.bcscs.org 1.888.888.0029

BC Cancer Agency

www.bccancer.bc.ca

Here to Help (for Mental Health)

www.heretohelp.bc.ca 310-6789

MS Society of Canada (BC)

www.mssociety.ca 1-800-268-7582

Parkinson Society BC

www.parkinson.bc.ca 1-800-668-3330

Stroke Recovery Association of BC

www.strokerecoverybc.ca 1-888-313-3377

Find more resources on
www.familycaregiversbc.ca

article by Janet Dunnett continued...

They didn't seem to matter as much as the niggles still confronting me in the back of my mind. "Did that medication help or harm Mom?" or "what really caused those sores?" and, "was she really dying all those months that we fought to protect her right to comfort care?" And the big one for me, "Did she deserve the care she got or was it only because we twins were squeaky wheels?"

Judi wondered why I remained restless, focused still on the past, when there was so much else I could do with my new freedom? "Why don't you write a book about it?" she finally asked one day. "It might get the monkey off your back...and mine." We agreed there was plenty of material. My computer had terabytes of every email from our twin interactions as daughter on deck needing daughter at a distance to share the frustration, the worry and the challenge of noodling through options for the way ahead, every day for years. I had shelves of medication lists, memos and letters to every kind of specialist or administrator, journals, checklists and decision trees. I had piles of research of every new medical issue, and increasingly I was collecting work by thought leaders communing about new kinds of end of life care challenges. That archive needed either a dumpster or serious sorting. "That's a good idea," I agreed. "I'll write a book. Will you help?" Judi said she would always be there to bounce ideas, but I must take the pen.

That's how it began. The Dwindling, A Daughter's Caregiving Journey to the Edge of Life is a story of ten years of family caregiving, starting from the first hint of white water somewhere up ahead until Mom's last breath that Judi believed was a kiss goodbye. Writing became my caregiver convalescence. It took four years of writing and ripping and lurching through ten drafts. And as I wrote and rewrote, I gained distance, and that brought insight. I could see points of transformation in all of us involved in the decade of dwindling. I saw strength and wisdom I had not seen before, and I saw where it was absent.

The published memoir was much different than the book I'd set out to write. It zeroed in on what was universal to family caregivers. How did my twin and I take on the role in a family of seven children? What about the isolation we battled in the role and saw in so many others? What about that host of other

emotions felt by all of us? I revealed the fright of burnout compassion fatigue. I explored how we all found meaning and purpose and were symbiotic with each other all along the way. I told about how the health care system felt like a maze with dead ends and too few sweet spots. I explained how promised patient centred care proved to be an endless advocacy battle.



"Daring yet compassionate," gushed Gail Sheehy of Passages fame, when she read the book. "Dunnett will lead you through the isolation..." she added. Another reviewer, a best selling author in his own right but also a leader in the American hospice movement, called the book a mirror helping other caregivers to see themselves. The perspective of an American gerontologist and activist for better care pathways at the end of life in that country directed my next steps. "We need to tell our stories," she insisted.

I'd shared bits of early drafts and was surprised by how many readers said, "I know just what you mean". Was there more that I could do to make this not just one story but the trigger for an avalanche of sharing? With the book available now, on Amazon and in libraries and bookstores, I'm ready to embrace that new challenge. Encouraging other family caregivers to share their stories too seems like an idea whose time has come. We are like oxygen, I believe. We are essential yet we are invisible, and that isn't right. We're the ones who are often the voice of the one in the bed. And we're beside that bed after everyone else goes off shift. Our stories matter. So can we move the dial a smidgen towards quality in care at the end of life by boldly sharing what we know with the benefit of our experience?

I think we can.

Provincial Resources for Family Caregivers

Anti Fraud Centre

www.antifraudcentre.ca or 1-888-495-8501

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 website

www.gov.bc.ca/health.

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

BC Palliative Care Benefits Program

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

BC Seniors Guide (BRAND NEW!)

www.gov.bc.ca/seniors-guide or 1-800-663-7867

Available in English, Chinese, French & Punjabi. There is also a First Nations Guide.

Crisis Centre BC

<http://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

<http://findsupportbc.com>

HealthLink BC

www.healthlinkbc.ca

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

Here to Help

www.heretohelp.bc.ca

Pain BC

www.painbc.ca

The Nidus Personal Planning Resource Centre

www.nidus.ca or email: info@nidus.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.bcceas.ca

Your Voice Counts

Caregiver Engagement Program Opportunity

Would you like to help support the shift to patient and family centered care? Do you have an interest in improving the health system? Would you like to help us improve our services or participate in research? Join a growing group of caregivers (past or present) in BC who are volunteering to share their experiences, opinions and ideas. Here are some examples of past engagement opportunities:

- Take a survey
- Join a committee
- Attend a one-day forum with health care leaders
- Review a document and provide feedback



Family Caregivers
of British Columbia

Toll-free Caregiver Support Line 1 877 520 3267
www.familycaregiversbc.ca

We can help right now



Toll-free BC Caregiver Support Line 1-877-520-3267



info@familycaregiversbc.ca



www.familycaregiversbc.ca



Family Caregivers
of British Columbia

Save a tree

Get your quarterly edition of Caregiver Connection by email!

Sign up at www.familycaregiversbc.ca.

To receive a hardcopy of future editions of Caregiver Connection, please call Family Caregivers Society of BC toll-free at 1-877-520-3267 or email info@familycaregiversbc.ca. Bulk copies also available.

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.

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

Volunteer

Be a caregiver voice in working toward patient and family centred care.

Call toll-free at
1-877-520-3267

or donate online at
www.familycaregiversbc.ca

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Publications Mail
Agreement #40040515