

CAREGIVER CONNECTION



Family Caregivers
of British Columbia

— Let us help —

30 YEARS

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The Caregiver Dance with Uncertainty

By Lycia Rodrigues, FCBC Caregiver Support Lead
and Wendy Johnstone, Gerontologist and FCBC
Consultant

Currently, many caregivers are taking on new or additional responsibilities due to the COVID-19 pandemic. Looking after elderly family members and/or loved ones with disabilities or illness can mean less access to external services and more responsibilities for the caregiver. A contingency plan serves as a “caregiver safety net” for unexpected events. From a health problem to a car accident, caregivers may face emergencies of their own. A concrete backup plan includes information on the

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- What's in your estate bucket?
- Balancing work and caregiving
- CIHI study on Caregiver Distress update
- Practical ways to stay connected

*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

care plan, physicians and medications, as well as a list of who can be counted on to care for your family or friend if you are not able to.

Here are some suggestions for your contingency planning:

Initiate the conversation with the person being cared for about their preferences in the event the caregiver is no longer able to continue caring. Seek advice and support. Disease-based organizations, such as the Alzheimer Society and the Canadian Cancer Society can be valuable resources for creating a contingency plan.

Consider the additional costs increased care will require, such as private care or help with housework and grocery shopping. Research eligibility for financial tax credits or publicly funded services.

Create a binder with legal and medical information:

- Legal documents, such as a power of attorney, representation agreement, insurance cards and a copy of the long-term care insurance policy, if they have this type of insurance, and direction around emergency care (e.g., blood transfusion, do not resuscitate).
- Medication list and schedule: include a list of current medications including dosage and when they are given. Have enough medication for two weeks in case you cannot get to the pharmacy to refill prescriptions. Ensure all your medications have refills available and/or discuss with the family doctor about phone renewal as part of your backup plan.
- Physician and medical information: include a list of their physicians, doctors, clinics, pharmacy, contact information, medical history and any medical treatment summary.
- A packing list of essential items: this should contain what they need if they

leave home or require hospitalization.

- Care plan and daily routine: this will include a list of any care or support provided, recreational activities, diet, information about their likes and dislikes, etc. Make a schedule of what you do and when and provide enough detail so someone else can take over.

Organizing your circle of care:

- Expand your circle of care to include other family members, friends, or neighbours who may be able to help. You may need to look at publicly funded services, private care or non-profit organizations in your community. Ask yourself if one person can handle the care or if it can be divided among different people.
- Document a plan for greeting visitors in the home.
- Leave instructions on how to access any technology that you are using, i.e. Facetime or Skype so the care recipient can continue to stay connected.

CAREGIVER CONNECTION

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EDITOR'S NOTE

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

As our team collaborated to discuss the theme and accompanying articles for the Fall Caregiver Connection newsletter, the consensus was to continue encouraging caregivers to keep going and stay the course amongst great uncertainty. Through the Caregiver Support Call Line and Virtual Support Groups we have connected with many caregivers as they increase their caregiver planning and health precautions during the pandemic. Now, more than ever, caregivers need support and encouragement as they navigate a new environment. Our hope with this newsletter is that you feel our support through our chosen articles. Included are articles around contingency planning, estate planning and practical ways to stay connected during holidays and special occasions. We have a 2-part webinar series on Advanced Care Planning in September and October which you will find the recordings on FCBC's YouTube Channel. In addition, we are hosting a webinar on October 28th at 2pm PDT titled 'More Than a Visitor: Care Planning in a Changing Environment' with the Alzheimer Society of BC. The above articles and

webinars educate and empower caregivers to feel confident and equipped in their caregiver role, especially in changing environments. We have also included two educational pieces around The 3Ds (delirium, dementia and depression) and a review of the Canadian Institute for Health Information (CIHI) study on Caregiver Distress. The 3Ds article shows the differences and similarities between these three conditions in order to support early detection and reporting to a health care professional. And finally, a report on the first national release of the Canadian Institute for Health Information (CIHI) indicator on Caregiver Distress. Members of our team and a caregiver volunteer were directly involved in the Expert Advisory Group that developed the indicator. This indicator will help to highlight the importance of supporting unpaid family and friend caregivers. We hope you enjoy this issue and welcome your suggestions for future ones. Send us your thoughts through the 'contact us' page on our website: familycaregiversbc.ca/contact-us

From my heart to yours,

Kate Landreth

Webinar Highlights

Part 1: *Advanced Care Planning* with a focus on Representative Agreements

Part 2: *Advanced Care Planning* with a focus on Advance Care Directives with Connie Jorsvik (watch on our YouTube channel)

All webinars are recorded and can be found on our website and YouTube channel familycaregiversbc.ca/watch-caregiver-learning-centre

Upcoming. . .

October 28th, 2PM, *More Than a Visitor: Care Planning in Changing Environment* with the Alzheimer Society of BC and FCBC.

Register at

https://us02web.zoom.us/webinar/register/WN_z6woJmN-S3iQ3sPgZLJqSQ

November 19th, 10 AM, *Mindfulness Self-Compassion for Caregivers* with Patricia Williams. Register at

https://us02web.zoom.us/webinar/register/WN_s2VI8yhkSOWx_wPXKCGruA

The 3Ds: Delirium, Dementia and Depression

Sheila Armstrong, FCBC Caregiver Support Team

Distinguishing between Delirium, Dementia and Depression (3 Ds) can be confusing for caregivers as they all can cause poor judgment, decreased ability to communicate, impaired functioning and memory loss. But there are many differences between them.

Delirium is a temporary condition which comes on quickly, within hours or days. Some of the signs of Delirium are poor concentration, difficulty remembering things, confusion about time and place, lack of interest in things, personality changes, problems with eating or sleeping, sleepiness, and slowness to respond. Signs can come and go. Delirium usually lasts between one to seven days but can last up to a few months. Those who are at highest risk for developing a delirium include older adults, people with depression and/or dementia, those who have had surgery, especially hip surgery, people who have infection e.g., urinary tract or constipation. In one-word, delirium is primarily a disorder of mood. Delirium is treatable and should be treated quickly. If a person presents with signs of delirium, a health care provider should be contacted as soon as possible.

Dementia is a disorder of the brain. The progression of dementia is slower, often over months or years. Dementia affects different people in different ways. Dementia is most common in older adults, but aging is not a cause. Dementia affects memory, learning, mood, and behavior. The most common type of dementia is Alzheimer's. Some of the signs include difficulty performing familiar tasks; difficulty with problem solving; impaired thinking and difficulty learning new information; memory loss which affects day-to-day activities; not being able to find

things or thinking someone has taken or moved something; confusion about time and place; poor or decreased judgment, and changes in personality and behavior. In a word, Dementia is primarily a disorder of memory.

Depression is a medical illness which people might have throughout their lifetime or it may develop at any time in a person's lifetime as a result of a major life change e.g., death of a loved one; loss of independence or developing an illness or dementia. Some of the signs of depression are sleeping more than usual, loss of interest in hobbies or activities, low energy level, loss of or increase in appetite, difficulty concentrating, aches and pains, agitation and irritability, feeling guilty, worthless, hopeless or full of regret, thoughts of not wanting to live or of ending one's life. Signs of depression must be taken seriously and reported to a health care professional as soon as possible so that treatment can be initiated in a timely manner. In a word Depression is primarily a disorder of mood.

Delirium, dementia and depression are serious conditions with similar symptoms meaning that they can go undetected and untreated without recognition and early reporting to a health care professional.

If your loved one is experiencing symptoms of the 3Ds, it is important to take action quickly.

**Alzheimer Society of B.C.'s First Link®
Dementia Helpline**

English: 1-800-936-6033

Cantonese or Mandarin: 1-833-674-5007

Punjabi: 1-833-674-5003

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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What's in Your Estate Bucket?

Amy-Alexandra Jaworsky

Legalese is language used by lawyers and in legal documents that ordinary people find difficult to understand. Sad, but often true. For many lawyers, legalese creeps into their vocabulary during law school and continues throughout their law career. One reason is that using a legal term often captures a collection of concepts with a very specific meaning. One bit of legalese commonly used by estate lawyers is the phrase “passing inside or outside the estate” when talking about what happens to your assets when you pass away.

A good way to understand this concept is if you think about packing some of your assets into a virtual bucket (one that is dimensionally larger on the inside!) and leaving some of them outside the bucket. The items in the bucket are the things that “pass inside your estate” and these items are handled by your executor. The items outside the bucket are things that “pass outside your estate”, items that are usually dealt with by someone other than your executor (more on this below).

Inside the bucket would be things like bank accounts in your name, your vehicle, your household contents and basically anything that is held in your name alone. Things outside the bucket include, for example, property held in joint names (this could be real property held in “joint tenancy” with your spouse or another person, joint bank accounts where the intention is for the joint owner to keep the money after you pass away), registered plans that name a beneficiary (like your RRSP, life insurance, or your TFSA) as well as assets that have been transferred to a trust set up during your lifetime. Note that assets held in more than one name are only outside the bucket if they are held as “joint tenants”—sometimes you can have assets that are in more than one name but they are

not joint tenants, so it's important to check if you are not sure which kind you have.

So why does it matter if something is inside or outside of the bucket? Here are two reasons to consider: 1: Your Will only controls the things that are in the bucket and not the things outside the bucket; and 2: money will be taken out of the bucket before your beneficiaries receive their share of what is left in the bucket. Let's explore this some more:

1. Unless your Will says differently, your Will does not control the items outside the bucket. So your house held in joint tenancy will pass to the other person on title, your RRSP will go to the person listed as beneficiary in your bank's paperwork, your life insurance will go to the person listed as beneficiary on the insurance company's forms, etc. These items will get transferred by the entity controlling the item, usually fairly quickly, and without waiting for your Will to be approved by the court.

2. There is a specific order as to how money gets taken out of the bucket. Debts, income taxes, and probate fees get paid out of the bucket first. Probate fees are calculated based on the total value in the bucket (with some exceptions). If you are giving cash gifts or specific items to people, those are taken out of the bucket next. What is left in the bucket after that is called the “residue” of the estate—this is what the remaining beneficiaries divide according to the terms of your Will.

Knowing what is in the bucket and what is out of the bucket is important to understand, particularly when you are aiming to treat your beneficiaries equally. So consider, what's in *your* bucket?

Amy-Alexandra Jaworsky is a Victoria lawyer practicing in the areas of wills, probate, residential real estate and corporate matters. amy@viclawfirm.ca / 250.858.0344

Balancing Work and Caregiving

Wendy Johnstone, Gerontologist & FCBC Consultant

You have a past-due deadline at work and your mother keeps calling because she is confused about what day it is and where you are. You are notified by your dad's long-term care home that he's fallen again and needs an x-ray as soon as possible. You are late for work after taking your spouse, who was recently diagnosed with cancer, to a medical appointment that ran late, and your supervisor calls you into their office.

Sound familiar?

Over one third of Canadians adults combine paid work and caregiving.

The majority of caregivers experience the wonderful benefits of giving back to the person they are caring for and enjoy strengthened family relations. The strains of caregiving, however, can take their toll. For example, a quarter of caregivers report a change in employment, including refusing training opportunities, promotions, taking a loss of income or simply having to quit their jobs altogether. Almost 15 per cent report health and sleep problems, and over a third report emotional difficulties due to caregiving. As the COVID-19 pandemic continues, caregivers are now faced with a host of unique challenges, on top of an already full plate.

Plans for balancing caregiving and work vary tremendously, and no single blueprint works for everyone. Here are a few strategies to lighten your load and reduce stress.

Check in with yourself regularly by asking:

- How is my current self-care?
- How resilient do I feel?
- What do I need for support?
- Where can I find extra support?

Be honest and proactive. Describe the situation to your employer before it becomes a problem and let them know you are committed to your job. Be honest with yourself. Don't sugar-coat the situation; it won't help you in the long run and can cause additional stress.

Learn what support is available. Can you work flexible hours? Do you have someone who can cover for you if you need to leave the office? Does your employer know about your eldercare situation? Are you comfortable talking to your direct superior or colleagues about your eldercare situation? What policies does your company have in place to support working caregivers?

Document, Document, Document. Create a file to keep track of information about your current caregiving situation. Good documentation serves as a valuable reference when dealing with your employer, colleagues, doctors, and others involved with the person you are caring for.

Put on your own oxygen mask first. Taking on a caregiver role often happens when life is already full. Many caregivers try to squeeze it into a busy life without letting anything else go. Try identifying what comfort or activity can help meet your needs. Self-care is about finding ways to meet your needs, and to feel better, cared for, and more grounded.



BC Family Caregiver Involvement in Design of National Caregiver Indicator

By Janet McLean, Evaluation and Quality Improvement Lead

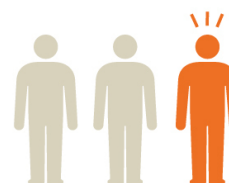
There is a saying in health care circles, “Nothing about me without me”. It speaks to the importance of including patient and family input in health sector work to ensure it is informed by lived experience. Last year, the Canadian Institute for Health Information (CIHI) put these words into action. In a process spanning 11 months, Imre Otvos (an FCBC caregiver representative) and I participated in an Expert Advisory Group to assist with the development of a national caregiver distress indicator. The process was well thought out and executed, involving a wide range of experts from across the country, representing a variety of disciplines and positions within the health care system. It was encouraging and exciting to be included and our caregiver perspective was welcomed and valued.

For the first time in Canada, caregiver distress will now be systematically measured and compared across provinces and territories. The first public data release occurred on August 6th. On a national basis 34.7% of caregivers are in distress. Over a third of caregivers whose care recipients are receiving home care services are experiencing feelings of distress, anger, or depression to the point

where they no longer feel able to continue caregiving. These caregivers are often spending the equivalent of a full-time job providing care and 70% are assisting with personal care activities such as bathing, eating, dressing, and mobilizing. This is critical information for health system leaders and policy makers who allocate resources in health care. Given that caregivers provide the



More **1** in **3** of these caregivers are distressed



CIHI

majority of care in the home, it is important that they have access to appropriate levels of services and supports.

When asked about his involvement in this work, Imre said, “I hope I contributed to a shared appreciation of caregivers. The Caregiver Distress Indicator will highlight the importance of supporting unpaid family/friend caregivers to those who have the power to make it happen”. Imre cared for his wife Irena for 15 years prior to her passing last summer, 13 of those in their home. His experience has made him a valuable advocate for caregivers, ensuring their voice is factored into plans for future support.

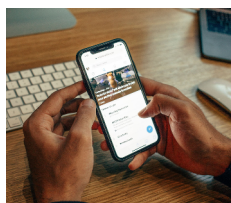
Missing Special Occasions: Practical Ways to Stay Connected

Kim Davis

Face-to-face gatherings play an important role in many of our lives. Whether it is birthdays and Christmas, or just a simple, backyard BBQ, getting together with our “tribe,” our friends and family, helps us feel connected, safe, and part of something bigger. Caregivers often speak of a sense of isolation and social gatherings provide connection for caregivers.

So how do caregivers, and others supporting vulnerable family and/or friends, fill this deep, human need in the midst of a pandemic? While nothing can truly replace participating in person, there are ways and technologies—Skype, Zoom, telephone, text, video messages, or even good, old-fashion snail mail—to help people share special occasions and have meaningful contact with others. Here are a few ideas:

1. Pick up the phone



While texting and social media now dominate many people's communications, the sound of a friend or loved one's voice—its tone, cadence and rhythm—can

make you feel like they are in the next room. If you can give them your full attention, you may even “hear” their facial expressions.

2. Meet for a virtual meal



Video apps are not just for work meetings or calling your family. Consider a virtual drink or dinner via Skype or Zoom. Set a date; maybe plan to cook the same meal “together”. A

shared favourite perhaps. Whose ends up looking tastier?

3. Find your “tribe” online



The Internet abounds with online groups and social media pages that you can join. If you cannot find one that suits your fancy, consider forming your own with a few

friends or socially distanced family; any Pygmy Rabbit enthusiasts out there?

4. Fashion a letter



Receiving a personal letter, or even a thoughtful email, can be an unexpected delight. In our age of rapid-fire tweets and prolific emoji, taking the time to put pen to paper, or

even chicken-peck a hearty e-note, can be a touching gift for both of you.

Face-to-face gatherings may be unsafe for some time yet, but thankfully there are other ways to celebrate community, have meaningful conversations and connect with those that touch our hearts and nourish our souls.

"Realize that we as human beings have been put on this earth for only a short time and that we must use this time to gain wisdom, knowledge, respect and the understanding for all human beings since we are all relatives."

—Cree Proverb



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

Join Our Virtual Caregiver Support Groups

Caregivers Connect: BC's Virtual Support Group
Thursdays | 2-3:30pm PDT

BC Men's Virtual Support Group
Second Tuesday of Each Month | 7-8:30 PM PDT



A podcast for family and friend caregivers

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 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)

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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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Be a caregiver voice in working toward patient and family centred care. Contact us for more information.



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