CAREGIVER CONNECTION





Janet McLean, Family Caregivers of BC

We have a saying at Family Caregivers of BC (FCBC) that "when you meet a caregiver, you have met one caregiver". It underscores the fact that each caregiver is unique. Every caregiver has their own personal situation and relationship with the individual they are caring for and the details pertaining to the care recipient are also distinct. These differences are what make services like our Caregiver Support Line and Caregiver Coaching so valuable. Combined with our locally-operated caregiver support groups and our support of groups across the province, we listen and stay in touch with the needs of caregivers.

Many factors influence the needs of individual Continued on page 2

In this issue

- FCBC is launching a podcast
- Caregiving for someone with a hip fracture
- How to evaluate the credibility of health websites
- Tired? Learn how to manage sleep better
- Bounce back from stress and worry

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

caregivers. For example, length of time as a caregiver, medical status of the care recipient, caregiver employment status, where the caregiver lives, access to and comfort with online resources, etc. The challenge we have at FCBC is covering the range of caregiver needs in a way that is as accessible to everyone as possible. A common phrase used to describe this approach is, "we try to meet you where you are". This requires ongoing adjustment.

We have an extensive hub of online resources that we update and flesh out as needs evolve. In the last couple of years, we have added a caregiver online learning module and two digital flipbooks. In addition, we have invested considerable time organizing content by popular topics so caregivers can find relevant resources quickly. We also try to stay abreast of new topics. A good example is our recent webinar on Medical Assistance in Dying. The federal legislation introduced in 2016 has raised many questions for care recipients and their caregivers. We consider it our job to make factual information available to caregivers so they are aware of options that may affect their caregiving. We don't necessarily endorse content.

As we continue our work with the Ministry of Health's Patients as Partners Initiative, our next venture is into the world of podcasts.

Podcasts are essentially radio shows that can be saved online and downloaded for convenient listening anywhere, anytime with supporting technology. They typically run 20-30 minutes and provide an opportunity for a conversational approach to topics. Our intent is to bring you podcast content directly from caregivers and our hope is you will hear yourself and feel community. We are excited about this new way of connecting with you. Stay tuned for information about our first season.

We count on you to let us know how we are doing. And we encourage all feedback—good and bad. Never hesitate to call or email us to let us know what you think and if there is anything you would like us to cover. We are listening.

STAY TUNED
Family Caregivers of
BC is launching a
podcast for the
caregiving community
in 2020!

CAREGIVER CONNECTION

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Family Caregivers of BC

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www.familycaregiversbc.ca

EDITOR'S NOTE

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

I attended my condominium's annual holiday festivities last night. At one point I was chatting with an elderly man who lost his wife some time ago and a delightful young woman who is expecting her first child. When I responded to the question about where I work, the young woman said "Caregiving – it is such a "HUGE OTHER".

I thought it was an apt description for a role so many of us will fulfill in our lifetimes yet one we don't typically anticipate or even acknowledge – unlike becoming a life partner or a parent. That is until it happens to us. Then we know how the HUGE OTHER can take over our relationships and the rest of our lives.

At Family Caregivers of BC we are working to increase awareness about caregiving so caregivers understand they have taken on a role in addition to the relationship they have with their care recipient. To do this we are working with points of first contact e.g. health care providers and organizations who operate in the health system to ensure caregivers are identified and referred for support.

Two of the articles in this issue of The Caregiver Connection have been contributed by health care providers. One is about an

eLearning module created for people caring for someone recovering from a hip fracture by a team at the University of British Columbia and the other is about the BounceBack program, delivered by the Canadian Mental Health Association, for people struggling with low mood, stress and worry. The issue is rounded out with an article about how to evaluate the credibility of Dr. Google by the Canadian Agency for Drugs and Technologies in Health and an excellent article on sleep by Canadian Virtual Hospice.

We hope you will find something of relevance to your situation and share with other caregivers who may be juggling the HUGE OTHER.

As always, thanks for caring. Our team at Family Caregivers of BC wishes you all the best in this New Year.

Janet

RECENT WEBINAR RECORDINGS

Family Caregiver Decision Guide

Dr. Carole Robinson, Professor Emeritus, UBC October 2nd

Medical Assistance in Dying

Dr. Rosanne Beuthin, Island Health

November 5th

Ability411 – Reviewing Technology Aids

November 26th

Listen to a wide variety of webinar recordings online for free at familycaregiversbc.ca /events/webinars

CAREGIVERS' ONLINE EDUCATIONAL RESOURCES FOR AFTER HIP FRACTURE

Maureen Ashe, Dolores Langford, Patro Ariza-Vega

Breaking a hip bone (hip fracture) is a serious, and often life-changing event for older adults and their family members. Preventing fractures from happening in the first place is important, but equally important is to maximize recovery after the hip fracture, and then work on strategies to prevent any other injuries. Often, a fracture in the family is a reminder to caregivers to think about their own bone health and fall risk factors. This is especially important if they are to remain healthy to take on additional caregiving responsibilities during the recovery of their loved one.

Based on research from Granada, Spain and here in Vancouver, we previously described the important roles caregivers play in the recovery process after hip fracture. In Granada, Patro Ariza-Vega, a physiotherapist and occupational therapist, and team members, developed and tested an in-person workshop designed to support caregivers of people with hip fracture (Workshop in Spain)1. Some of the workshop information was based on resources developed in British Columbia (BC), called the Fracture Recovery for Seniors at Home, or FReSH Start². A key feature of the in-person workshop in Spain was to focus on the older adults' goals, and to promote doing daily activities with someone rather than doing it for them. In other words, a shift in thinking around how to support an older adult's ability to return to their usual activities of daily living.

Here in BC, we worked with the team from Spain to develop a similar program using an online e-learning course for caregivers of older adults with hip fracture. The course has three



main areas of focus: (1) management of the hip fracture recovery process; (2) preventing future falls and fracture, and (3) supporting caregivers' health, and preventing musculoskeletal injuries sometimes associated with caregiving. If you go to this link you can do the course yourself www.hiphealth.ca/blog/FReSHStart.

As part of our development process, we would like to have more feedback on the content of the course, and how we deliver these educational resources. If you are caring for someone who has or is recovering from a hip fracture, we would love to hear from you. We are looking for caregivers and people who have had hip fractures to help us identify ways to distribute and evaluate our e-learning course. If you have any questions, or are interested in joining our research team, please email maureen.ashe@ubc.ca.

- 1. Ariza-Vega P, Ortiz-Piña M, Mora-Traverso M, Martín-Martín L, Salazar-Graván S, Ashe MC. Development and Evaluation of a Post-Hip Fracture Instructional Workshop for Caregivers. J Geriatr Phys Ther. 2019;10.1519/JPT.000000000000230. https://pubmed.ncbi.nlm.nih.gov/30913137
- 2. http://www.hiphealth.ca/blog/FReSHStart

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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EVALUATING THE CREDIBILITY OF HEALTH WEBSITES: CAN YOU TRUST DR. GOOGLE?

Reprinted with permission from the Canadian Agency for Drugs and Technologies in Health (CADTH)

How to Tell if It's Legit

There are several tools available to evaluate health websites. Most of them list criteria that reliable websites should meet. Here is a summary of the main criteria to look for:

Author — The website should clearly identify the author, institution, and editorial board (the people responsible for the professional review of the content).

Date — The website should contain current scientific information, and the content should be updated regularly.

Objectivity — The website should be evidence-based and objective (factual) in its content, listing benefits and risks (e.g., side effects). The website should mention other treatment options, if available, including no treatment, and it should encourage patients to consult with a health care professional.

Purpose — The website should state its purpose clearly. Any advertising should be clearly marked and separated from the site's main content.

Transparency — The website should identify its ownership, sources of funding, and explain how it collects and uses personal information.

Usability — The website should be easy to use, well-organized, and well-designed. It should provide a way of contacting the owner of the site.

There will be some credible websites that don't meet all the criteria. Likewise, there will be unreliable websites that look very slick and seem to meet all of them. Ultimately, the only

Red Flags

- The website relies on single cases or personal testimonials.
- The information is presented in a sensational, overly emotional, or alarmist way.
- The website implies that a treatment affects everyone in the same way (e.g., 100% success rate).
- The website is trying to sell you something.
- It is not clear who the author is or what qualifications or conflicts of interest he or she has.
- Studies are referenced, but they are old (from 10 years ago or more) or the year of publication is not provided.
- Links are broken this could indicate that the site has not been updated recently and that the health information could be outdated.

way to know if online health information is accurate is to find the source and read the scientific study being referenced. Learning how to evaluate for the credible criteria, however, will help you start filtering.

Credible Canadian Health Websites Health Canada

www.hc-sc.gc.ca

Public Health Agency of Canada www.publichealth.gc.ca

Government of Canada: Health www.healthycanadians.gc.ca

SLEEP & CAREGIVERS

This is adapted version of the Canadian Virtual Hospice's article, "Sleep and Caregivers" and has been reprinted with their permission.

Adequate sleep is essential to staying healthy and functioning well. You need sleep to do your daily work safely, to cope with emotional stress, and to carry on giving care. Yet if you are caring for someone at home or sitting with someone round the clock in a care facility, you likely are not getting enough sleep.

Researchers have found that 95% of family members who provide palliative care have serious sleep problems. These problems are becoming better understood, and increased attention is being given to caregivers' sleep problems.

Family caregivers often minimize their sleep problems and hesitate to talk about them. You may feel your sleep is less important than what is happening with the person in your care. You may think you can get by with limited sleep and catch up in the future. Unfortunately, this lack of sleep is more likely to catch up with you.

What is sleep disturbance?

Sleep disturbance is any change from the way you usually sleep. It may be a change in how long or how well you sleep, and may include one or more of the following:



- difficulty falling asleep
- difficulty staying asleep through the night
- waking early in the morning
- · feeling unrested in the morning
- being sleepy during the day

Factors that contribute to caregiver sleep disturbance

Many factors contribute to poor sleep for caregivers. It may be one or a combination of the following factors:

Changes in routine

When you care for someone, you have less time for fresh air, exercise or relaxation, which promote sleep, and you may consume more caffeine which inhibits sleep.

Change in sleeping environment
 You may sleep on a couch or
 temporary bed to be near the person
 you are looking after. You may be
 disturbed by the nighttime noise made
 by special equipment, such as an
 oxygen concentrator, alternating
 pressure mattress, or even a baby
 monitor you may use to listen for calls
 for help.

Worry

You may have trouble falling asleep or may wake up in the night because your mind is busy thinking about your concerns.

- Lack of help with over-night care
 The programs and services in your area may be limited, which makes it difficult to find respite care at night. You may find it hard to hand over responsibility or trust the care provided by others. The person who is ill may not be willing to accept outside help.
- Needs of the person who is ill

 The person in your care may need help during the night with toileting, repositioning or medications. The person may have trouble sleeping if symptoms such as pain, shortness of breath or restlessness are not well controlled. If the person in your care is

unable to sleep, chances are you will be unable to sleep as well.

Effects of sleep disturbance

Regardless of the cause, your lack of sleep has consequences for you and for the person in your care. These are some of the common consequences:

- Your overall physical health may change. Your body may not be able to fight off a cold or flu as usual, or you may experience flare-ups of an existing health problem, such as high blood pressure.
- Your overall mental health may change. You may feel less able to cope with the emotional ups and downs and stresses of providing care. You may have memory problems, or trouble thinking clearly. Also, sleep disturbance has been linked with depression.
- Your lack of sleep may change the way you relate to the person you are caring for. You may be impatient, angry or resentful towards the person who is ill, or act in a way you later regret.
- You may feel sleepy or exhausted during the day and question your ability to carry out day-to-day activities or to provide care safely.

Managing sleep

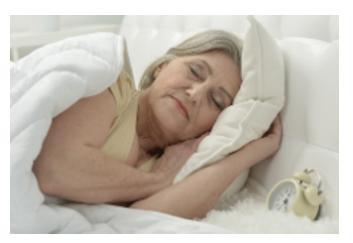
It is important to seek medical help about sleep difficulties. Try to be as specific as possible with a medical professional about:

- how much sleep you are really getting between the time you go to bed in the evening and the time you wake up in the morning,
- how often you are up in the night as a caregiver,
- how much you rest during the day.

Seek help from doctors, social workers, spiritual care providers, counsellors or hospice volunteers who may help you find ways to reduce your worries and link you to services and supports. Health care providers may also be able to help manage the symptoms the person you are caring for experiences, which can support better sleep for you both.

Many caregivers do not like to take sleep medication, because they worry about not hearing the person they are caring for or being too sleepy to provide care in the night. Talk to a doctor about the possibility of taking a sleep medication if other attempts to promote sleep have failed.

And don't be afraid to ask for help with caregiving. Asking for help is not a sign of failure. Sometimes it makes a big difference to have someone cover for you while you take a nap or sleep overnight two or three times a week.



What you can do

These are some things that may help you improve your sleep:

- Try to maintain a regular sleep-wake schedule.
- Try to grab even a few minutes every day for exercise and fresh air.
- Cut down on caffeine (e.g. coffee, tea, chocolate, cola) and nicotine (e.g. smoking) especially before bedtime.
- Nap when you can, but try to avoid the late afternoon and evening, unless you know you will be awake during the night to provide care.

- Minimize nighttime noise or light around you. Remove clocks also, unless you need to set an alarm.
- Identify, talk about and find ways to address worries and concerns before bedtime. Even small things such as making a list before bed can help clear the mind for sleep.
- Set up a bedtime routine that lets you unwind a bit before you turn out your light. It may help to have a bath, wash your face and hands, change into pajamas, brush your hair and apply lotion to your face and hands.
- Notice what helps you relax and make that part of your routine. You might listen to soft music, read a bit, watch a funny TV show, or pray.
- It may help to do some relaxation or visualization exercise.
- Have something warm to drink or eat

- before bed.
- Go to bed when you feel drowsy in the evening, rather than making yourself stay up until a set time. This helps you avoid lying awake in bed.

Canadian Virtual Hospice is a digital health care leader and the world's most comprehensive online portal for information and support on advanced illness, palliative care and grief. It serves the information and support needs of people living with life-limiting illness, families and caregivers, health providers, researchers and educators. It operates: virtualhospice.ca, portailpalliatif.ca, MyGrief.ca, MonDeuil.ca, LivingMyCulture.ca, KidsGrief.ca, DeuilDesEnfants.ca, LivingOutLoud.Life, vireAfond.ca, Methadone4Pain.ca, and numerous social media platforms.

BOUNCEBACK®: FREE SUPPORT FOR MANAGING LOW MOOD, STRESS AND WORRY

BounceBack® is a free, evidence-based program available to individuals (ages 15 years and older) throughout British Columbia and delivered by the Canadian Mental Health Association. The BounceBack® approach is based on cognitive behavioural therapy (CBT). CBT is recognized as one of the most effective ways of helping to build well-being and resiliency. The program supports thousands of individuals around the province every year and has been shown to reduce symptoms of depression and anxiety by half. There are three different program options you can choose from:

BounceBack® Coaching

A trained BounceBack® coach will help you learn skills to improve your mental health in up to six phone sessions, which you can do



from the comfort of your home. Your coach will guide you through the program materials, help you develop new skills, keep you motivated, and check in on how you're doing. You design your own program by selecting the workbook topics you'd like to focus on.

Coaching and workbooks are available in Continued on page 10

familycaregiversbc.ca

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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 Toll-free: 1-877-520-3267

Support groups can be found in the following BC communities:

Burnaby Campbell River Chemainus Comox Coquitlam
Cowichan
Cranbrook
Creston
Delta
Duncan
Fernie
Gabriola Island

Keremeos
Kimberley
Invermere
Ladysmith
Langley
Maple Ridge
Mayne Island
Nanaimo
Oliver

Pender Island
Penticton
Port Alberni
Port Coquitlam
Port Moody
Prince George
Richmond
Salt Spring
Island

Sidney
Smithers
Sooke
Summerland
Surrey
Vancouver
Victoria

English, French, Mandarin, Cantonese and Punjabi.

Golden

To access the coaching program, you will need a referral from a doctor or nurse practitioner. This referral is important to make sure that your health care provider matches you with the right support to meet your needs. If your doctor refers you for coaching, you will be contacted within five days to set up your first appointment with your coach.

BounceBack® Online

If you'd like to work through the program materials on your own, the online program might be a good fit for you. The online program is made up of a number of modules focused on providing help with addressing stress, depression and anxiety. The modules include videos, e-books and worksheets that you can work through at your own pace. No referral is required to access the online

program. If you'd like more support, the option to switch over to the coaching program is available by getting a referral from your doctor.

BounceBack® Today Video

This 45 minute video offers practical tips on managing your mood, sleeping better, increasing activity, problem solving and healthy living. The video is available online or in DVD format, and in multiple languages including English, French, Mandarin, Cantonese, Punjabi, Farsi and Arabic. You do not need a referral to access the video or DVD.

To learn more about BounceBack®, get a referral form, or access the online program or video, visit www.bouncebackbc.ca.



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)

λγ)

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

1-877-952-3181

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

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

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





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