# CAREGIVER CONNECTION





# Who's Who in the Hospital Zoo

By Connie Jorsvik, owner of Patient Pathways

When you or a loved one is seriously ill or injured, you will find yourself pushed into the deep end of the healthcare system. Knowing who's who in the zoo and what their role is can help you to survive and thrive.

As quickly as possible, find out who the key healthcare professionals are on the hospital unit where your loved one is receiving care.

Find out who the nurse is running the unit on a day-to-day basis. Their name is different in just about every hospital and every unit (examples: charge nurse, patient-care coordinator, nurse manager, head nurse). This nurse is usually there for several shifts in a row and has *Continued on page 2* 

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Family Caregivers of BC is a registered non-profit dedicated 100% to supporting family caregivers.

BC Caregiver Support Line 1-877-520-3267

familycaregiversbc.ca

ongoing knowledge of all the patients and what the nurses, doctors, physiotherapists, and occupational therapists are saying and doing. Introduce yourself and ask for an overview of the layout of the unit, phone numbers, best times to call, and when doctors are most likely to make rounds.

Write all this in your notebook.

#### Who is who?

Registered Nurses (RN): They are often key allies in getting information and keeping you in the loop. Write down their names, and the dates and times of the shifts they worked (in case something goes wrong, but also if you later want to send a thank you).

**Unit social worker (SW):** Can be a key resource for all things non-medical such as emergency financial resources, psycho-logical supports, and are often a key-player in planning for discharge or transfer to other units, services, and home.

**Physiotherapists (PT):** The key people in getting patients physically activated, transferring from bed to chair and toilet, walking, and strong enough to get home. Ask to be taught how to help with physical exercises.

Occupational Therapists (OT): They help with assessment of how a patient can do their activities of daily living (eating, bathing, dressing, toileting, and self-care). The OT will be responsible for assessments for where your loved one will go next: rehabilitation, residential care, or home. They are key players in discharge planning and any equipment that will be needed if the patient is going home.

**Physicians:** These are the key players you are likely to see the least. Who the doctors are, depends on the unit the patient is on, and the size of the hospital. If the patient is in a smaller hospital, the family physician will likely remain involved and may be the lead physician.

In larger hospitals, on general nursing units, hospitalists (who are general practitioners or

internal medicine specialists) are assigned to be the lead in patient teams. They usually will have rotations of a week or two, so there is consistent medical care.

In critical care and intensive care units, specialists will likely lead the teams and are on duty or available 24 hours a day. In large teaching hospitals you may never see the lead physicians and specialists, as all care will be overseen by Residents.

Wherever possible, ask questions about who the doctors are and try to get an understanding of their rotations and availability.

Most Responsible Physician/Practitioner (MRP): This is the physician or nurse practitioner who is ultimately responsible for the patient's care. This role is most often used in larger hospitals, and when multiple specialists are involved in care, and the role is often assigned according to the primary reason the patient was admitted to hospital (cardiology, neurology, orthopedics, internal medicine).

Sometimes, the MRP gets lost in the shuffle, especially when the patient is moved from a critical care unit to a nursing unit. It is very useful to know who your MRP is and to keep them looped in the patient's care.

This information is from Connie's book: "Advance Care Planning: Plan ahead for Serious Illness - Chapter One."



# May Spring Bring You Hope



By Victoria Lougheed
Education and Learning Lead, Family Caregivers of BC

As we move from winter into spring, the world around us begins to come alive again. As the days grow longer, buds form on tree branches and spring bulbs send shoots up through the soil. It is a time of reawakening, and an opportunity to look at the good things we have in our lives. This newsletter is themed around the hope that spring brings for ourselves, our care recipients and the future. Not the distant future, but the coming year.

Lycia Rodriguez has written a beautiful piece about the power that hope can bring to us. It can reframe how we see the world. In choosing hope, we choose positivity, and this can be pivotal to our mental health. Our Dear CSL column provides some excellent resources for mental health. As caregivers, maintaining our own mental health is essential to our happiness, and the well-being of our care recipients. Sage Schmied has penned an informative piece about emotions, what they mean, and how we can reframe them in a productive way. Just in time for volunteer appreciation week, Stacey Dawes has acknowledged the essential contribution of our FCBC volunteers over the past year. FCBC relies

on our volunteers to carry the torch in sharing our mission, vision, and resources with caregivers across the province. The work they do is key to our success. Finally, I have put together a piece around the importance of embracing choice as a caregiver. This article echoes the tone in Sage's piece - reframing how we look at our choices is empowering and positively changes the nature of our caregiving relationships.

I hope you enjoy this newsletter and the articles shared within. May the season bring you warmth, sunshine, and the seeds of growth that will flourish for the coming year.

As always, if you need support, an ear, resources, or information, please reach out to our Caregiver Support Line at 1-877-520-3267. You can also find resources on our website at www. familycaregiversbc.ca.

Sincerely,
Victoria Lougheed

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







### FCBC Thanks Our Volunteers!

By Stacey Dawes, Volunteer Management Lead, Family Caregivers of BC

Our volunteers have made extraordinary contributions to support caregivers this past year and wee want to acknowledge and honour these efforts. Volunteers are invaluable to Family Caregivers of BC and to our community.

These are truly unprecedented times, and thanks to the determination and selfless acts of many volunteers, our collective response to the coronavirus pandemic is something we can be very proud of. Volunteers create caring, collaborative, and compassionate communities.

During National Volunteer Week 2022, we celebrate the contributions of FCBC's volunteers: their actions, their understanding, and their genuine concern for family and friend caregivers.

Volunteering connects people from diverse backgrounds and life experiences, expanding our views. It can build our capacity to work collectively and contribute to a vibrant, inclusive society.

This past year, our volunteers have:

 Pivoted to providing virtual support groups when in-person groups closed.
 Not only did they switch their own groups

- to online, but because of the huge need in the province, they stepped up to offer virtual groups for all caregivers in B.C., as well as a men's-only virtual group
- Provided insight into the needs of our caregivers during the pandemic and the importance of self-care. Because of this insight, our volunteers launched and facilitated our Intensive Journal Workshop
- Grew organizational knowledge by conducting interviews, engaging with other organizations to gather information on other caregiver supports for accurate referrals and providing a caregiver voice by engaging in research, surveys and committees

The commitment and dedication our volunteers have shown in supporting British Columbia's family and friend caregivers is something that all of us at FCBC will be forever grateful for.

Thank you for helping to make the present and the future a place where caregivers are valued, supported and recognized as partners in care. If you are interested in joining our volunteer team, please do not hesitate to reach out!

For more information, please visit our website.



# **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 wellbeing, 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 well-being.

Adapted from Robert S.
Stall, M.D. (2002)Caregiver's
Handbook, Buffalo, New York.

Find resources to help you on Family Caregivers of BC's website: familycaregiversbc.ca

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

# Dear Caregiver Support Line

I am a caregiver for my partner who has multiple health concerns as well as chronic fatigue. I've noticed her mental health deteriorating as we change her treatment plans. She has been off work and is dealing with a new level of isolation. I want to help and support her, but the situation has also taken a toll on me. I realized my own mental health is struggling. I have low energy and my mood is constantly fluctuating. Any suggestions and support you can give me would be appreciated.

Mel

Hi Mel,

Thank you for contacting us at Family Caregivers of BC. The way you are feeling makes a lot of sense with the recent changes you and your partner are experiencing. It is important to recognize your own needs at the same time you are caring for your partner. Here are several mental health support options that may be relevant to/may interest you:

Here to Help BC provides an overview of services available across the province including crisis/support lines, free/paid counselling, and courses. You can <u>visit their website</u> for a directory of these services.

Some of these services are described in more detail below.

#### **Mental Health/Crisis Lines**

There are a few mental health crisis lines that are good to know about should you ever need more immediate confidential support.

The BC Crisis Centre has several supports focused on your situation and needs:

- Crisis Line 1-866-661-3311
- Seniors Distress line 604-872-1234
- Suicide Prevention line 1-800-784-2433

- KUU-US Crisis Response Service
   1-800-588-8717. This is a culturally aware crisis support for Indigenous peoples.
- Prideline BC 1-800-566-1170, peer support, information and referrals for LGBTQ2+, weeknights from 7-10pm.

The BC Crisis Centre also has a youth chat and general chat on their website if you are ever unable to speak on the phone. This service can provide follow-up calls and support in over 140 languages.

310 Mental Health Support Line offers emotional support, information, and resources specific to mental health and substance abuse across BC. Call 310-6789 (no area code) 24/7 to connect.

#### **Online Courses for Mental Health**

Bounce Back is a free skill-building program for youth and adults experiencing low mood, mild-moderate depression, and anxiety. This is an online or phone program with a coach (up to 6 sessions). You can watch videos and instructional materials in several languages and resources are available on their website.

CBTSkills.ca is a small group learning experience to develop CBT skills, which may help with mental health. The course is covered by MSP if you attend all the sessions or just miss one session. The initial upfront cost is \$65 (reimbursed at completion) and you can choose to pay \$35 for the workbook or access it online for free. This course can be taken multiple times and has great reviews.

Recovery College, part of the Canadian Mental Health Association, offers online courses in many topics related to mental health and substance use. Courses are free and are usually a few sessions long. You can search for courses and take any online ones from any location: Online Mental Health Courses - CMHA National.

#### **Low-Cost Counseling**

The provincial government has extended their funding to community resources that offer free or low-cost counselling. There are several ways to search for the services near you.

The Community Action Initiative keeps a list of community services that provide counselling by Health Authority. <u>Visit the website</u> to view what is available near you and what they offer.

To search for virtual mental health supports based on your demographic or your needs you can <u>visit</u> this website through the Government of B.C.

Finally, the Affordable Therapy Network provides a directory of practitioners in your area or who

offer online services at low cost or sliding-scale prices. This is a nice option to <u>search directly for a counsellor</u> to see if they would be a good fit for you and your needs.

#### **Additional Mental Health Supports**

For help finding additional mental health supports you can try the BC211 Resource Database (visit online or phone/text 211). This free resource in over 150 languages, is dedicated to helping British Columbians find the support they need.

For more caregiver-specific tools, resources and peer support information, call our BC Caregiver Support Line at 1-800-520-3267. We look forward to your call!

# You Can Count on Hope

By Lycia Rodrigues, Caregiver Support Manager, Family Caregivers of BC

I am invigorated by the stories of caregivers using our support services during the pandemic and their experiences of hope and meaningful connection.

Much of caregiving – especially during the pandemic years - occurs within the context of hopelessness. Loss of income, out-of-pocket medical expenses, unintended consequences of social distancing, loneliness, a lack of time for self-care. Within this milieu, it is common for one to ask themselves, as I have done multiple times, why hold out any hope?

I have often felt uneasy about the concept of hope. The Hebrew and Greek equivalent of the English word "hope" means confidence or expectation that something wished for will happen. However, I agree with author Kate Bowler, who says, "It's very confusing to figure out what hope means if hope is a history about the future and the future is never certain."

I have tried to understand hope as this pandemic continues to overwhelm. The idea of wise hope by Roshi Joan Halifax has helped me to understand that "hope is not seeing things unrealistically but rather seeing things as they are. It's when we realize we don't know what will happen that this kind of hope comes alive; in that spaciousness of uncertainty is the very space we need to act."

I appreciate the writer Elizabeth Gilbert and her sense of hope based not on a confidence in happy conclusions, but the conviction that something makes sense. Thus, with wise hope we can face caregiving realities, address them while remembering what else is present.

This spring season, we invite caregivers to attend our virtual and in-person support groups in B.C. and other new FCBC activities. We believe that caregivers can make choices about the types of support they need. We offer diverse styles of facilitation, creative group activities, training, workshops, and webinars to inspire a sense of wise hope among caregivers, staff, volunteers, and our communities of practice.

# **Emotions in Caregiving**

By Sage Schmied, Greater Victoria Caregiver Wellbeing Project Coordinator, Family Caregivers of BC

Emotions can be tough. We all have them, yet we are often not taught a lot about them. In many ways, we get the message that emotions are wrong or bad. And there's no doubt about it: caregiving can bring a lot of our emotions to the surface. Providing care to a loved one can be challenging and overwhelming. I can tell you that all the emotions you feel are completely healthy.

You may not think of emotions as being healthy, but they are. There is a biological reason behind every emotion. They helped us survive and allowed us to adapt to our surroundings. Emotions are the first way humans communicated to others and interacted with their environments. The core emotions of sadness, fear, disgust, anger, and joy tell us what we need and how we need it. For example, fear kept us safe from potential harm and joy connected us to each other.

How do you notice your emotions protecting or connecting you? How are they helping you adapt to your situation?

Asking questions about the emotions you feel. Being curious is an important way to begin reframing your response to them. From an early age, you may have been told to be strong and not cry, or that your anger made you dangerous. Guilt and shame can arise when you feel something you were taught not to feel. These feelings are simply another way your nervous system protects you! Realizing that these emotions are healthy, that they are communicating important things, can shift some of negative beliefs about them.

If it feels scary to begin to shift these thoughts, know that you're not alone. First, simply acknowledging the emotions you are feeling is a good step. Let them be what they are. Next, try to understand and reflect on their purpose. What are they telling you? Finally, try to see them in a









different way. It is your choice to view your emotions in whatever way works for you. It can be helpful to use imagery or metaphors to begin acknowledging and thinking about your emotions differently. One example is included below.

Imagine a dinner where all the guests at the table are the emotions you are feeling at a given moment. It could be a dinner date for two, or a party of 10. Any emotions are perfectly acceptable. What image comes to mind when you think of each one? What thoughts do you notice attaching to them? Are some emotions very quiet? Are others loud and eating all the food at your dinner? Your emotions are a part of you but not all of who you are. Feeling ashamed doesn't make you a shameful person. Feeling angry doesn't make you an angry person. It just means you are human, and your nervous system is working!

Suggestion: Practice a daily mantra with yourself to reframe some thoughts and feelings that may be difficult. Here are some phrases that could work:

"I am enough"

"My emotions are valid"

"I accept the way I am feeling right now, even if it is not what I want to feel."

#### Resources

The Biology of Emotions | <u>Brain & Behavior Research</u> <u>Foundation</u>

Our 5 Core Emotions And How We Make Them So Complex.

### The Power of Choice

By Victoria Lougheed, Education and Learning Lead, Family Caregivers of BC

A commonly reported stressor in caregiving is feeling like you have no choice about it. You may absolutely love the person you're caregiving for, but still feel it was forced upon you. Why?

When we choose our actions, we feel in control of our lives, which lowers stress. This works both for caregivers and care recipients. But how do we change our perspective on our caregiving situation? We have to reframe it and look at it as a conscious choice. We have to make the choice for ourselves, and we must try to provide our care recipients with as many opportunities for choice as they can handle. This empowers them and helps them feel that essential control over their own destinies.

You can choose to make a new choice in your life at any time. You can stop, reexamine your situation and make a new choice. Having the power to choose gives you a sense of control.

# Four ways to embrace choice as a caregiver

#### 1. Don't keep score

If you have family that don't or can't participate, you need to reframe your expectations of how they can be part of the care team. If you don't already have one set up, I invite you to look at our resources around building a circle of care.

In my family, caregiving is shared between my husband and me. He does some things and I do others. I don't waste energy tallying what I've done today vs what he has. I know we both do our best.

#### 2. Ask others to do more

Look at what tasks you must do, and where others can help. Even if you are the only one available, do you have to go get groceries or can you have them delivered?

If you offload some tasks to a family member, friend, or a delivery service, you need to detach yourself from the outcome. It may not be done as you would have done it. But it will be done.

#### 3. Practice a one-day-at-a-time philosophy

This is something I've really taken to heart. Due to the nature of my daughter's disability, I can't guarantee any planned outings or activities will happen. I had to learn to release myself from expectations, and just go with the flow. Some days are great, others less so. Things got much easier when I learned to swim with the current instead of fighting it.

Another way of practicing this philosophy is to focus on what I have power over and let go of what I don't. I have more control over today than I do over next year. Worrying about next year isn't going to help me get through today.

#### 4. Make your choices conscious ones

This falls into the category of positive self-talk. It's a tool of cognitive behavior therapy that has proven time and again to be very effective. Simply repeating, "I choose to be a caregiver for my loved one today" reminds you that this is a choice you're making and puts you into the mindset of having some control over your experience. It helps you feel empowered.

Creating your caregiving experience instead of reacting to it changes how you look at yourself, your role, your care recipient and your situation together. It can empower you, too. Scheduling time for yourself is important. If you have a plan in place, it's easier to keep the self-care commitments you've created.

#### Choice and Receiving Care

Care recipients often struggle with a feeling of losing control over their day-to-day lives. If they need a caregiver, it means there are pieces they can no longer manage on their own. It's frustrating to live your entire life in an

independent way and then lose autonomy as you age, or when medical situations arise.

#### Four ways to increase choice for recipients

#### 1. Give choices where you can

This can help your care recipient regain some control over daily life. Something as simple as choosing their own clothing can be very meaningful. But try not to overwhelm them with choice, especially if they are dealing with Dementia or Alzheimer's.

#### 2. Go with the flow

Try to build a bit of flexibility into your daily routine. It will help you both. If it's a sunny day, maybe a walk outside can go ahead of a household chore you need to get done. You'll both benefit.

#### 3. Focus on the positive

I found this a struggle until I started doing a gratitude journal with my daughter. We were both feeling depressed, and I hoped it would help us. It did! We end each day by writing down three things we felt good about or enjoyed. Then we talk about them. We don't always come up with three things. Some days we may not find one, but

then remember that tomorrow is a new day and that's something to be happy about.

#### 4. Encourage independence where you can

It's easier to do it yourself. Any parent can tell you this. As you provide care for your care recipient, always keep an eye out for how they can participate in the tasks of daily life, or activities they can do themselves. Encourage it. Celebrate it and you'll both feel more positive.

#### Resources

The Dance Between Guilt and Resentment

**Boundaries for Caregivers** 

<u>Create your caregiving experience, don't just</u> react to it

Family Caregiver Decision Guide

Caregivers Decision Guide webinar

Building a Gold Medal Support Network

Where to Draw the Line: Boundary Setting for Caregivers

# Join a Community Caregiver Support Group

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

Visit <u>www.familycaregiversbc.ca/get-help/other-community-supports</u> to find details on caregiver support groups in your community.



Support groups can be found in the following B.C. communities:

Abbotsford Burnaby Campbell River Chilliwack Comox Valley Coquitlam
Cowichan Valley
Cranbrook
Delta
Gabriola Island
East Kootenay
West Kootenay
Keremeos
Lake Country

Langley

Mayne Island
Nanaimo
North Vancouver
Oliver
Pender Island
Penticton
Port Alberni
Port Coquitlam
Princeton

Maple Ridge

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

# Disease/Condition Specific Caregiver Support

ALS Society of BC

1-800-708-3228

**Alzheimer Society of BC** 

1-800-667-3742

First Link Dementia Helpline

1-800-936-6033

**BC Brain Injury Association** 

604-984-1212

**British Columbia Schizophrenia Society** 

1-888-888-0029

**BC Cancer Agency** 

bccancer.bc.ca/contact

Here to Help (for Mental Health)

310-6789 (no area code; free available 24 hr)

**HSC British Columbia Resource Center** 

604-822-7195

MS Society of Canada (B.C.)

1-800-268-7582

Parkinson Society B.C.

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

**B.C. 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

#### **B.C. Ministry of Health**

www.gov.bc.ca/health

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

 Visit <u>www.patientsaspartners.ca</u> for the free self-management activities offered through Patients as Partners

#### **B.C. Palliative Care Benefits**

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

#### **BC Seniors Guide**

www.gov.bc.ca/seniors-guide 1-877- 952-3181 PDF available in English, Chinese, French, Korean, Vietnamese, Punjabi and Farsi. Hard copy available in English, Chinese, French, Punjabi

**Crisis Centre BC** 

<u>crisiscentre.bc.ca/contact-us</u> 1-800-SUICIDE

(1-800-784-2433)

#### Family Caregivers of British Columbia

www.familycaregiversbc.ca

Caregiver Support Line: 1-877-520-3267

**Find Support BC** 

findsupportbc.com

First Nations Health Authority

www.fnha.ca Toll-free: 1-866-913-0033

HealthLink BC - medical

www.healthlinkbc.ca

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

Here to Help - mental health

www.heretohelp.bc.ca

Pain BC

www.painbc.ca

The Nidus Personal Planning Resource Centre

www.nidus.ca | info@nidus.ca

**Seniors First** 

www.seniorsfirstbc.ca

SAIL - Seniors Abuse & Information Line

Vancouver - Metro 604-437-1940

Toll Free: 1-866-437-1940 (8am-8pm daily)

Language Interpretation (9am-4pm M-F)

www.seniorsfirstbc.ca

**UBC Pharmacists Clinic** 

www.pharmsci.ubc.ca/pharmacists-clinic

# We can help RIGHT NOW



BC Caregiver Support Line 1-877-520-3267 Toll-free, available Mon/Wed/Fri at 8:30am-4pm and Tues/Thurs at 8:30am-7pm



info@familycaregiversbc.ca





www.familycaregiversbc.ca



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