

CAREGIVER CONNECTION



Family Caregivers
of British Columbia

— Let us help —

30 YEARS

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Creating a Circle of Care for Caregivers: Mobilizing Informal Respite

By Lycia Rodrigues, Family Caregivers of BC Caregiver Support Lead

At Family Caregivers of BC, we understand the importance of relationships in our lives and the need for strong support networks. Establishing a circle of caring people or support network has been a strategy used by people in diverse cultural traditions all around the world for many years. A circle of care is especially important for someone who might be vulnerable because of health and social concerns. Many of us have friends or informal networks that we rely on when we need advice, when we are in crisis and when we want to share and celebrate our triumphs. For many caregivers, these typical

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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

www.familycaregiversbc.ca

connections may not exist automatically and need facilitation. It can be difficult to describe exactly what a circle of care is or what it does because each support network is unique, and there are as many possible circle arrangements as there are circles.

Our approach at FCBC is to first support a caregiver to identify people that could be in their circle of care (including family, friends, neighbours, community members, etc.), and then guide the circle of care group to meet on a regular basis to help the caregiver maintain their wellness. The circle of care group in essence strengthens and develops the caregiver's informal network of support. A circle can involve two or more people who collaborate to share information and provide whatever type of support the caregiver has identified as a need. They could make follow-up phone calls, help with paperwork and bill payments, grocery shop on a specific day, walk the dog, or do laundry and cleaning. When you are a part of a circle of care, you enter into an intimate and vulnerable space where you learn about the private aspects of a person and their care recipient's life. In this space, vulnerabilities are exposed, fears and

dreams shared, and common visions developed. The circle comprises community members and at the center is the family caregiver. The family caregiver guides decisions about who to invite to be part of the circle and the direction in which the circle's energy is employed.

The Greater Victoria Caregiver Support Program at FCBC has facilitated the Circle of Care for Caregivers model in recent years and has seen and heard of the value it brings to caregivers, but also to the people who are part of the support system. We received inspiration from the model developed by the Cowichan Family Caregivers Support Society "Circles of Support Strengthening Personal Networks for Caregivers and Seniors" (Jodie MacDonald, 2015), and this Spring, our Provincial Support Program launched our first offering of the Circle of Care for Caregivers training. This training supports community organization's staff and volunteers to provide guidance on how to use this approach within their caregiver support program.

Our goal at FCBC is to increase informal respite options for caregivers by mobilizing informal supports. If you would like to learn more about this model, please see our recommendations below.



Want to learn more about Circle of Care?

BC Caregiver Support Line: 1-877-520-3267 or email cgsupport@familycaregiversbc.ca

Listen to our Caregivers Out Loud Podcast Episode,
Friends Caring for Friends, A Circle of Care Approach
www.familycaregiversbc.ca/podcast/episode8/

Watch our Webinar: Build a Gold Medal Support Network
www.familycaregiversbc.ca/video/build-a-gold-medal-support-network/

Editor's Note

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



It is hard to believe that it has been one full year since Janet McLean handed the Caregiver Connection Newsletter torch over to me. This past year I have been continually amazed by the dedication and enthusiasm of our small, but mighty FCBC team to ensure that family and friend caregivers are seen, heard and celebrated. But more so, I have been humbled by the hard, yet rewarding work that you do as caregivers.

I have been fortunate this past year to interact with you through our webinar platform, Facebook Live sessions, podcast episodes, and emails sent in from our website. And most recently, during Family Caregiver Awareness Month, I was thankful for the honest and real experiences you shared through writing for our blog and Enews, and participating in our Caregivers Out Loud Podcast Listening Party. Your insightful stories, feedback and comments help and inspire me to continue educational programming that resonates and supports you.

This summer issue is packed like a full beach bag with information and examples about different types of caregiver support. Lycia Rodrigues, FCBC's Caregiver Support Lead, describes the Caregiver Circle of Care approach. This is an informal way for caregivers to identify and receive supports from family, friends, and community members. Please also tune into our podcast episode, *Friends Caring for Friends: A Circle of Care Approach* that also speaks to this topic

(www.familycaregiversbc.ca/podcast/episode8/). Rick Lauber shares his own caregiving experience and advice in the article, *Planning for Caregiving – Is Your Suitcase Completely Packed?* Rick is a former co-caregiver and an accomplished author with experiential caregiver insight. We also include a new section in our newsletter this month called, *Dear Caregiver Support Line*. Our *BC Caregiver Support Line* gets many questions from caregivers across British Columbia. This month we answer a question from a family caregiver on the topic of navigating the health care system, specifically hospital discharge. Dr. Daren Heyland, Founder of Plan Well Guide, shares his expertise and knowledge on caregiver planning in the article *The Power of Planning Well*. And last but not least, our new digital flipbook called *Caregiver Support Plan: Making it Personal* has been a big hit with caregivers and we have curated and included valuable information about creating your own caregiver support plan in the article *Putting Together Your Personalized Support Plan*.

Pour yourself a cold lemonade and enjoy the articles and resources that aim to support your caregiver experience.

From my heart to yours,
Kate Landreth

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Planning for Caregiving – Is Your Suitcase Completely Packed?



By Rick Lauber

Itinerary, passport, plane tickets, hotel reservations, camera, extra clothes ... packing for a trip takes a great deal of planning. Becoming and serving as a caregiver for an aging parent, a friend, a child, or a spouse/partner can be

a trip as well requiring similar planning. Having a set route to take also greatly reduces the anxiety and potential family squabbling.

Caregiving isn't always simple for everybody. Family members must take on new responsibilities as caregivers, balance their own lives, and watch as someone they know mentally and physically weakens. Cognitively aware seniors may realize that they are losing their prized independence and must hand over much of that control to their children.

Taking preliminary steps, including the following, can help a caregiver plan and will make this process easier:

Prepare Yourself Emotionally

A caregiver's emotions can change from day to day or even minute to minute. When Dad was in long-term care, I laughed, cried, felt frustrated and didn't even know what to feel. Losing a family member (or even anticipating this loss) can be immensely challenging and rightly so—you are losing someone you likely care for deeply. To better manage, build yourself a strong support circle—the people you know, trust the most, and who will be empathetic to your situation.

Plan for Crises

If there is one thing that COVID-19 has taught us, it is that emergencies can happen. Knowing the future is impossible, but caregivers need to explore

options as to how to respond if—and when—something unexpected occurs. A worldwide pandemic isn't the only crisis to consider ... a long-term care facility in St. Albert, Alberta (just north of Edmonton) recently went up in flames and all the residents had to be evacuated. A senior could fall and sustain a serious injury. A senior's health could suddenly worsen.

Read the Will

Many difficult decisions may have already been made by a senior when they were better able to do so. Carrying out these requests can be intense but also comforting as family caregivers will not have to decide what might be best for a dependent adult who may not be able to decide what is best for them.

Rick Lauber is a former co-caregiver, a published book author, and an accomplished freelance writer. Lauber has written two books, Caregiver's Guide for Canadians and The Successful Caregiver's Guide as valuable resources for prospective, new, and current caregivers. He has also served as a voluntary Board of Directors member for Caregivers Alberta. www.ricklauber.com.



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

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.

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: www.familycaregiversbc.ca

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

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

Dear Caregiver Support Line

This is a new addition to our quarterly Caregiver Connection, where we answer questions from family and friend caregivers.

My husband is being discharged next week and I'm worried about having him come home and not knowing what to do or what to plan for. How do I best plan for hospital discharge?

~ Worried Family Caregiver

Dear Worried Family Caregiver,

Hospital discharge can feel exciting and stressful for both the person being discharged and the family caregiver. One way to make the transition as smooth and safe as possible is to request you be included in a discharge planning meeting in the hospital.

At this meeting, the patient's care team will meet to discuss the plan as well as answer questions you as a family caregiver may have. Professionals involved may include the attending or family physician, the Clinical RN in charge, a discharge planner, family caregivers and the patient. Other health professionals, e.g., a physiotherapist, social worker or occupational therapist may also be asked to participate. If no arrangements have been made for a discharge planning meeting, you can make such a request. This is especially helpful if you have questions or concerns about the discharge process. The best person to arrange a meeting is the Unit's Patient Care Coordinator (PCC), Discharge Planning Nurse, Unit Manager, or Social Worker.

The discharge planning meeting provides essential information about the patient's condition, care needs and supports needed at home. It also presents an opportunity to discuss any concerns and challenges. The meeting process and plan include:

- Providing patients and their family caregivers with information, support and resources to reduce the risk of complications and increase

the opportunity to ensure continued recovery from a hospital stay;

- Discussing what phone calls to expect from community supports, i.e., a phone call from an occupational therapist to do a home safety check or a home care nurse for wound management, etc.;
- Reviewing medications, scheduled time for medications and any changes made;
- Reviewing what to expect for recovery and going over warning signs and problems to watch for, including what to do and who to call if there is a problem; and
- Discussing what follow-up appointments are needed and with whom.

Logistics of discharge can also be included in this meeting, such as:

- Discussion of the arrangement of any required home care support services for the home. This can be organized through the Health Authority or through a private pay agency;
- Identification of mobility supports for the care recipient;
- Identification of environmental home limits that would impact safe care; and
- Transportation arrangements.

Getting a written copy of the discharge summary is a must (where possible) as well as any recent test/procedure summaries when leaving the hospital. If referrals were made it is also advisable to ask for a list of these referrals and how the referral is being processed.

The following are reasons when it is especially important to request a discharge planning meeting:

1. You do not feel your loved one should be discharged from the hospital.

2. As a caregiver you see barriers to providing safe and adequate care when your care recipient returns home, for example, your living space is too small to allow for a hospital bed lift equipment. Or you may not be able to organize the necessary mobility equipment on short notice.
3. You foresee the need for home care support services and are unclear as to what will be provided by community services or how they will be put into place.
4. You think the transport home will be an issue.
5. As a caregiver you feel emotionally and/or physically unable to provide safe and adequate care under these new conditions.

If you feel that you are not being heard and are

being pushed toward an unsafe discharge, you can further request to speak to the following individuals, in this order: Discharge Planning Nurse, Unit Manager, Patient Care Quality Office for the hospital (the contact information for this office is usually posted near most elevators), Director of Nursing, Director of Medicine.

Good communication between all essential partners in care prior to discharge can alleviate any anxiety you, the caregiver may feel about any new responsibilities in providing care in the home. A discharge planning meeting can be key in ensuring that the transition from hospital to home or a care residence is as seamless as possible for all involved.

Sincerely,

The Caregiver Support Team

The Power of Planning Well

By Dr. Daren Heyland, Founder of Plan Well Guide

Worried about what might happen to you or a loved one you are caring for if they were to get seriously ill? With the COVID-19 pandemic continuing to forage on, it has left many people feeling overwhelmed and wondering how long both this feeling and the pandemic will carry on for. As a critical care physician and researcher who has been studying communication and decision-making when patients are seriously ill for more than 20 years, I am unfortunately all too familiar with people who have not thought ahead to prepare and plan ahead for their future medical care. Consequently, patients and families experience considerable stress when making time-sensitive life and death decisions and, ill-prepared patients are more likely to get the 'wrong' medical care. This is why Plan Well Guide (www.planwellguide.com) was created. The goal of this free website is to help individuals understand the different types of medical treatments offered, and with a deeper sense of knowledge, help individuals communicate what



is important to them, so that they can share that information with their loved ones and their health care team and get the medical care that is right for them.

In these current times, it is more important than ever before that individuals do their Advance Serious Illness Planning (ASIP). You may be reading this and thinking what exactly is ASIP and how does that differ from advance care planning (ACP)? Traditional ACP focuses on end-of-life planning under to conditions of certain death. It is similar with legal documents (Representation agreements) that you may have filled out where there is language like “When I am dying, this is what I want or don’t want, etc.” Unfortunately, this language is not helpful and may even be harmful as it causes confusion when applied to a serious illness where there is some uncertainty about whether you will live or die (for more on this read this blog at planwellguide.com/chapter-19/). Serious illness is like a bad COVID-19 pneumonia, a severe stroke or heart attack, or being in a bad car accident, where there is a probability you may die, but there is also a probability you might recover. The concept of ASIP is about putting your values, goals and preferences into a planning document, so when you are ill and can no longer make decisions, your doctors, substitute decision-maker and your family can refer to it. The output of Plan Well Guide is a ‘Dear Doctor’ and ‘Dear Substitute Decision-Maker’ letter, so they have a written record of your values and preferences.

By planning your medical care in advance and sharing information with your family members, you can significantly reduce their stress and anxiety when they are called upon to make decisions for you. And, you are more likely to get the medical care that is right for you!

Think about it in the context of your role as a caregiver. If your loved one were hospitalized with COVID-19 or another type of serious illness, they most likely won’t be able to think or speak for themselves and the doctors will want to speak to someone to help make life and death decisions. Has the care-recipient formally designated a substitute decision-maker? Is that

you? Do you or the formally designated substitute decision-maker know how best to represent their wishes when making life and death decisions? Do you know how medical decisions are made and how to advocate for the best care for your care recipient?

I understand that for many, these scenarios are difficult to consider; however, the alternative to not discussing them is far worse. To help guide you through this planning process, Plan Well Guide offers a free online course that will walk you through creating your Advance Serious Illness Plan, so you will:

- Be educated about the different types of medical care and treatments
- Be able to express your values and goals
- Get done-for-you documents to allow for easy sharing and communication

The online workbook is designed to help you make informed decisions about your medical care. It takes you step-by-step through thoughtful consideration of your values, preferences, and different types of care. We don’t want to overload you with information, therefore the workbook will always save your progress and you can pick up where you left off as many times as needed.

When it comes to advance serious illness planning, by failing to plan, you may be setting yourself up to fail! If you don’t plan ahead, you are more likely to get the wrong medical care and you will be adding to the stress and anxiety that family members experience when called into making life and death decisions without proper guidance and instruction. I encourage you to do your ASIP, ASAP at www.planwellguide.com/

For more BC resources on Advance Care Planning and times when you need health care and can’t speak for yourself visit: www2.gov.bc.ca/gov/content/family-social-supports/seniors/health-safety/advance-care-planning



Personalized Caregiver Support Plan

By Wendy Johnstone, Provincial Program Consultant and Gerontologist with Family Caregivers of BC

Caregiving is on a continuum and along the caregiving journey, situations change, transitions happen, care needs of the recipient change and caregiving needs change. While uncertainty is a certainty with caregiving, a caregiver support plan can give you a foundation and strategies to help you navigate the ups and downs and twists and turns. It allows you to think about how best to care and what supports will help. It also allows you to better manage what's in your control and what is not.

Without it seeming disrespectful or uncaring, caregiving can be seen as a "project". All well executed projects have a plan. And all projects require support. Knowing what you need as caregiver and strategies for supporting those needs are the foundation of your plan.

The following steps provide one approach to creating a plan for yourself:

1. Identify your needs: Check in with yourself regularly by using a self-evaluation, found at www.familycaregiversbc.ca/wp-content/uploads/2021/03/FCBC-Understanding-Caregiver-Needs.pdf, where you can identify areas where more support would help and where you are having trouble or want to fill a gap in your caregiving strategies. For Cathy, her needs include having time for herself during the day and an opportunity to take part in a support group.

2. Reflect on your current caregiving activities: Identify which of your current activities require your presence and which can be delegated. Ask yourself, are there activities that someone else can do? This delegation allows you to share the care and decisions with others. It also helps to create boundaries and balance your limited time, while establishing a circle of care and support around you and your care recipient. For Mike, he needs to better understand medication management but realizes he doesn't need to help administer it. He wants to delegate this task to community health services.

The Many Faces of Caregiver Needs



Cathy is caring for her spouse who has significant memory loss but no other major health problems until a serious fall landed him in hospital.



Mike is caring for his mom with a long history of undiagnosed mental health challenges, back pain and diabetes. She's being discharged from the hospital with one page of instructions and new prescriptions.



Anna is a student who is caring for her sister with kidney disease and is just learning to navigate dialysis and the care routines at home.



Mandy is caring for her spouse with terminal cancer and is struggling with the emotional drain that accompanies caring for a dying family member.

3. Find your carrot: Write down why these needs are important to you. How will it help you with your overall wellbeing and as a caregiver? For Anna, her need is to understand how dialysis works so she can support her sister in being as independent as possible. Her carrot is: 1) she wants to support her sister to feel empowered in decision-making and in managing her disease and 2) knowing what is expected of her in a caregiving role will allow Anna to manage her school schedule so she can still graduate.

4. Detail your plan and find support: Keep it simple by writing down your plan. You can use our tool at www.familycaregiversbc.ca/wp-content/uploads/2021/03/FCBC-Caregiver-Plan.pdf or find your own template to use. Finding support can include finding and utilizing resources like friends, family, local organizations, self-management programs, or your family doctor, etc. We suggest you decide on one or two supports that are likely to be the most helpful

in meeting your needs. For Mandy, her needs were dealing with feelings of sadness and grief. She spoke to their case manager and to the local hospice organization. She was able to find a counsellor that was a good fit for her needs.

5. Prepare for setbacks: They happen. Think about who can help you with your needs. Or think about what might get in the way of filling your needs. How might you get around these things? If possible, create a plan to deal with possible setbacks. For Mike, a possible setback would be his mom not wanting anyone else helping with medications. His plan is to use the case manager, whom his mom really enjoys, to support this conversation with his mom.

6. Visualize your success: How will your well-being and caregiving be different with more of your needs met? What type of reward will you enjoy?

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 www.familycaregiversbc.ca/family-caregiver-support-groups/ to find details on caregiver support groups in your community.



Support groups can be found in the following BC communities:
Burnaby
Campbell River
Comox Valley
Coquitlam
Cowichan Valley

Cranbrook
Delta
Gabriola Island
East Kootenay
West Kootenay
Keremeos
Lake Country
Langley
Maple Ridge

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

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)

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 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
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

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



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Toll-free, available Mon-Fri, 8:30am-7pm



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