

NEW TO CAREGIVING:

HOW TO PREPARE AND WHAT YOU NEED TO KNOW



**Family Caregivers
of British Columbia**

— Let us help —

Introduction

“Knowledge is a weapon. I intend to be formidably armed.”

— Terry Goodkind

Being a caregiver can creep up on you. Maybe it starts by dropping by your mom’s house and doing her laundry or taking her to a doctor’s appointment. Maybe you call your adult daughter with depression every day to check in. Then you find yourself doing the grocery shopping and refilling prescriptions for your mom. Your daughter starts calling you to make her dinner a few times a week. Gradually, you find yourself doing more and more. You may not even realize it; you are making a commitment to care for someone else.

Sometimes, caregiving is triggered by a major health event or acute diagnosis, such as a serious fall, motor vehicle accident, stroke, heart attack or cancer diagnosis. Maybe you suddenly realize that dad’s memory lapses have become more serious or maybe your wife was diagnosed with cancer. Life as you know it stops, and all your energy goes to caring for the person who is ill.

And in an instant, caregiving becomes your new normal. People new to caregiving often feel:

- ♥ They don’t know what they don’t know
- ♥ They are getting lots of information and trying to sort out who is on the health care and service provider team
- ♥ They are unsure of what resources or programs exist for the person they are caring for
- ♥ They want to learn to speak up and support themselves as a caregiver
- ♥ They want to learn how to support and speak up for the person they are caring for

We hope this flipbook helps give you more information and support on how to prepare to care and what you need to know.

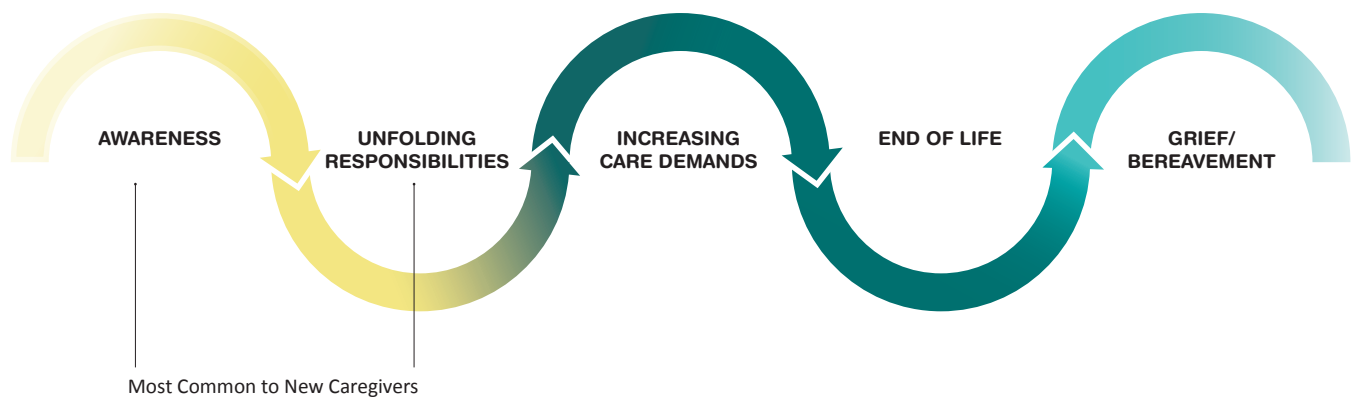


Phases of Caregiving

Even if caregiving is a common experience, your role as a caregiver will vary across the time you are caring. The length of your role and the intensity will vary depending on the care recipient's disease. Your role will be very dynamic and may take on very different directions at any given time.¹

For caregivers who are being faced with this new role, they often are most entrenched in the awareness and unfolding responsibilities phases. The phases of caregiving are not linear; it depends on so many factors of the caregiving situation.

Generally speaking, the caregiving phases² are:



Learn more about what it means to be a caregiver

Use our [Are You a Family or Friend Caregiver?](#) tool to find out more.

Identifying as a caregiver

“Knowing yourself is the beginning of all wisdom.” — Aristotle

Caregivers may not always think of themselves as a caregiver but rather in terms of their relationship such as a spouse, parent, adult child, neighbour, etc. Regardless of the relationship you have with the person you are supporting and caring for, it's important that you add the tag “caregiver” to the list of things you are.

Without identifying yourself as a caregiver, it will be much harder to find the right resources and support that can help you in your new role.

What does being a family caregiver look like or mean?

Definition of a Family/Friend Caregiver:

Family member or friend who provides care and support to someone living with disease, disability or frailty due to aging. The role of family caregiver is mutually determined by the people providing care and support and those receiving it.

If you help someone (or a number of people) in your life or community with any of the following activities, you are considered a family/friend caregiver:

-  Transportation
-  Home maintenance, inside or out
-  Personal care, such as helping with a bath/shower, and getting dressed
-  Attending appointments (health care or other) to take notes and help with follow up
-  Banking, paying bills, managing finances and legal concerns
-  Handling Crises and arranging for assistance, especially for someone who cannot be left alone, i.e. ER visit, hospital discharge or responding to a visit to the Emergency Department
-  If you are providing support or care from afar
-  Meal preparation, cleaning, dishes
-  Running errands/getting groceries and/or going out to do errands with the person
-  Medical procedures or treatments, including medication management
-  Coordinating care, support services or appointments
-  Talking with doctors, nurses, care managers, and others to understand what needs to be done
-  Visiting or regularly calling to ensure someone is safe and has their day-to-day needs met
-  Providing emotional support (listening to concerns, talking about how they are feeling, problem-solving and making decisions, etc.)



Getting started in your new role

Where to start?

There is no crystal ball with caregiving. Given the complexity and everchanging role of caregiving, caregivers often feel better when they are prepared and supported. Here are some concrete ways for you to start supporting yourself and the person you are caring for.

Finding Information

The first stages of caregiving can feel the most challenging. Caregivers often feel very uncertain about the future, feel the least informed about what's happening, what's needed and expected. Finding the right information is a first step. Caregivers are often most concerned about:

- Needing to know what just happened with the person they care for
- Needing to know what this means for the health and wellbeing of the care recipient and how their life will change
- Needing to know how this would change their life as a caregiver

Get the best possible diagnosis: It may take a lot of calls, tests and appointments with the family doctor and specialists but caregivers and the person they are caring for find it very helpful to know what disease they are dealing with.

Determine what supports you need: This is a very important (and often the most difficult and time consuming) step is to determine what supports you need (informational, emotional, access to publicly-funded and private resources). You should try to be as specific as you can be. For example, if the person you are caring for had a stroke, you may need more information about aphasia, the type of stroke and how it affected the brain, mobility aids and communication & rehabilitation available in your community.

Learn what specific skills you need: Depending on the diagnosis, learn what specific skills and training you need. Who can help you with proper training and skills? Start with your health care team. Disease specific programs

and caregiver support are also helpful. For example, you may be faced with a complicated medication regime or a rehabilitation program or transferring someone from a wheelchair to bed. Different skills and information are needed depending on the diagnosis. For example, caring for someone with frontotemporal dementia, is very different from caring for someone with diabetes or someone on dialysis.

Tips for New Caregivers:

Find out as much as you can about the disease affecting the care recipient. Here's where Family Caregivers of BC can help. We have just about every kind of handout, webinar and workshop to support you in your role as a caregiver. We also recognize it can feel overwhelming and time-consuming to sift through websites and links so we've narrowed our focus to come up with our [Caregiver Learning Center](#).

If you need to find out or research information and resources, consider divvying up your list with family and friends. Many of them want to help but probably don't know how. Giving them a concrete task will help you and will also help them. Also, your health care professional is helpful in directing you to information.

A caregiver's perspective on what she needs, "Carol, who is caring for her son with schizophrenia, shares what she put in her caregiving backpack in the first year, "information about my son's disease, skills and understanding to deal with his behavioural challenges, problem-solving techniques (trial and error), many reminders about boundary setting, knowing what keeps me resilient, selfcompassion and respite." She adds, "Yes, it's a big backpack and it takes time to fill it with the right items. But this is what helped me the most!"



Get Your Paperwork Organized

Discuss what planning is needed – financially and legally. This would include taking steps to identify programs and resources that might provide financial relief, advanced health-care directive representation agreement, power of attorney, a will, etc. You can find a comprehensive guide to financial resources [here](#).



Explaining your role

Patient and family-centered care is an approach to health care that respects the central role caregivers play in a care recipient's life. Increasing awareness of your role to health care professionals is one way to help voice your needs. Margaret, who cares for her husband, Ron finds she needs to remind their family doctor and specialist about her part on the care team. Ron is recovering from a stroke and has mobility and memory issues. She respectfully might say, "I know Ron is the patient and we are here to talk about his medical needs but it isn't just him going through treatment and recovery. Ron and I work together to manage his recovery plan and it's helpful for me to be part of the care planning."



Asking for help

Ah, the biggie! Most humans find it hard to ask for help. When you're a caregiver, it can be even harder. About 30% of caregivers have unmet support needs³. This can mean caregivers experience higher levels of reported daily stress and lower self-reported mental health. Learning to accept help early in your caregiving role and knowing who to ask will make it easier down the road. FCBC can help by listening, providing emotional support and answering questions related to caregiving. Call our toll free line (BC) at **1-877-520-3267**. We're available Mon-Fri, 8:30am to 4pm.



Build a Gold Medal Support Network

Caregiving can have a negative impact on social relationships. Connections fall away as symptoms appear, the family changes, and people don't know how to help. By thinking of our family, friends, neighbours and acquaintances as part of a "circle" surrounding us, we can embrace the idea that support is essential for caregivers and shouldn't be left up to chance. To learn more about creating a support network, listen to one of our most popular webinars [here](#). Don't forget to download the handouts!



Build your personal resilience

Regardless if you end up caring for one year or 6 years, building resiliency is one way to help decrease caregiver burden. Resilience helps make the hard parts of caregiving do-able. Building resilience helps caregivers sustain their health and capacity to care, both for themselves and others. When caregivers feel resilient, it can expand their capacity to move through difficult situations that are part of their caring role and reduces their susceptibility to stress⁴. We've got you covered with our very own [Building Your Personal Resiliency flipbook](#).



1 R. C. Talley, J. E. Crews (eds.), Multiple Dimensions of Caregiving and Disability, Caregiving: Research, Practice, Policy, DOI 10.1007/978-1-4614-3384-2_2, © Springer Science & Business Media New York 2012

2 R. C. Talley, J. E. Crews (eds.), Multiple Dimensions of Caregiving and Disability, Caregiving: Research, Practice, Policy, DOI 10.1007/978-1-4614-3384-2_2, © Springer Science & Business Media New York 2012

3 Statistics Canada. (2019). Support received by caregivers in Canada. Catalogue no. 75-006-X. ISSN 2291-0840. Retrieved from: https://www150.statcan.gc.ca/n1/en/pub/75-006-x/2020001/article/00001-eng.pdf?st=iaMxP1_i

4 McCraty, Rollin. (2011). Coherence: Bridging personal, social and global health. *Activitas Nervosa Superior Rediviva*. 53. 85-102

“In my own deepening understanding of myself I find my capacity to serve others is deepened as well. The better I am at self-care the more genuinely nurturing of others I am able to be.”

— Mary Anne Radmacher

Reaching out to us for support

what you can do right now and how we can help

For [emotional support or questions](#) related to caregiving, call our toll-free line (BC) at 1-877-520-3267. We're available Mon-Fri, 8:30 am to 4 pm. When you call our Support Line, we listen as you share whatever is on your mind. When we answer support calls, our goal is to listen with compassion, remembering that while there are common themes, each caregiving experience is different and so are the needs. If we feel you could benefit from more one to one support, and/or are moving through a complex situation we can also refer you to our [1:1 Caregiver Coaching for more complex situations — see if you qualify.](#)

Visit [The Caregiver Learning Centre](#): We recognize it can feel overwhelming and time-consuming to sift through websites and links. We've narrowed our focus to come up topics that address the most commonly expressed questions and concerns that we hear from caregivers (e.g. caregiver well-being, financial information, health care navigation and more!).

To receive news and information to your inbox, [sign up](#) for your newsletter and e-news.

Want to learn more about how to be a caregiver? Listen to our prerecorded sessions by [webinar](#). These free educational events cover your high-priority questions. And listen to our podcast, [Caregivers Out Loud](#).

Join a [family caregiver support group](#) and learn from other family caregivers and share your advice to help others.



Family Caregiving: Don't do it alone.

Visit your online Caregiver Resource Centre:

www.familycaregiversbc.ca



Family Caregivers of British Columbia

— Let us help —

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