

Finding and Using Your Voice as a Partner in Care

A RESOURCE FOR FAMILY AND FRIEND CAREGIVERS



Family Caregivers
of British Columbia

— Let us help —



BRITISH
COLUMBIA

Supported by the Province of British Columbia



Introduction

YOU ARE a partner in care. You know that and we know that. Yet sometimes it might not feel like that.

It might be hard – and downright intimidating – to speak up. It might be hard to communicate in order to be heard by others when you are frustrated, angry, or confused. You might leave appointments with more questions than answers. But you know your role and voice are important; you are managing many aspects of care and know the person you are caring for better than anyone. While our health system has embraced the patient and family-centred health care approach, it will take time to transform how family and friend caregivers are included on the front lines of care.

Caregiver researchers have identified family caregivers want to be partners in care. They want:



Recognition of, and respect for, the caregiving role.



To be **included** in care planning of the person they are caring for.



To feel **informed** with timely communication based on their needs and role.



To be **empowered** to look after their own health and well-being, and gain knowledge, skills and confidence in their caregiving role.^{1,2}

Caregivers and health care teams are continuing to learn how to work together in supporting patients. Changes can take time but as Martin Luther King Jr once said, “If you can’t fly, then run, if you can’t run then walk, if you can’t walk then crawl, but whatever you do you have to keep moving forward.”

¹ British Columbia Ministry of Health. Patient, Family, Caregiver and Public Engagement Framework 2018. <https://www2.gov.bc.ca/assets/gov/health/about-bc-s-health-care-system/health-care-partners/patients-as-partners/patients-as-partners-framework.pdf>

² Patient and Family Centred Care Resource Kit: How to Improve the Patient Experience at the Point of Care. (2014) Alberta Health Services. Quality and Healthcare Improvement. Engagement and Patient Experience Department

The Importance of Being a Partner in Care

Health systems work well in acute situations like broken bones, heart attacks, etc., but managing multiple chronic conditions such as dementia or mental illness can be more challenging. The main reason is that people with complex chronic conditions move across care settings. This requires the support of various health care professionals, including family physicians, specialists in medical and social care like geriatricians, pharmacists, mental health, and home care case managers. Access to and coordination of housing, transportation, and community services all need management. Care recipients and caregivers may also need legal services like capacity assessments and power of attorney.

As a caregiver, you are often managing a lot of these areas, along with the care recipient, and can provide health care teams with valuable input. Being a partner in care is critical because:

- ♥ Information you provide is important and as dependable as a medical record.
- ♥ Care planning and management are often one of your primary responsibilities.
- ♥ You often manage the continuity of care.
- ♥ Your observations and input help to make sure the person being cared for is assessed and diagnosed.

Family Caregivers as Partners in Care

Why They Should Be Included



Financial and Legal



Managing Medications



Health Advocacy



Monitoring Health



Housing Needs



End of Life/
Palliative



Transportation



Community -
Based Services



Emotional and
Cognitive Health
of Care Recipient



Home support/care
and instrumental
activities of daily living

Family Caregivers are managing many aspects of care and often know the care recipient better than the care team



Finding and Using Your Voice as Partner in Care

This isn't just for the person you are caring for – it's also for yourself.

Building a strong network. One of the keys to managing a caregiving role is to have a reliable network of formal and informal support, including a trusted team of compassionate, competent, and caring people.

Raising your hand to say you need help is the first step – a huge one – and something many caregivers put off until it's too late. Secondly, raising your other hand and having your role or work being recognized by the health system is an important way to use your voice – for yourself and the person you are caring for.

Identify your needs. There is a saying, “If you’ve met one caregiver, you’ve met one caregiver.” Diversity means that one size will not fit all; caregivers need to know about their unique needs, goals and required supports to support their personal situation.”

In Michelle’s case, here is what she said about knowing what her needs were:

“I realize I can’t really be of full service to my husband and the care team if I don’t understand my needs. And I don’t know what supports and resources may help me. So that was a key starting point for me – identifying my needs.”

I struggled with three areas: 1) how do I support my husband to be as independent as possible within his capacity, 2) how do we ensure that he is getting the best possible care from his care team and 3) how do I keep myself afloat and not lose my own self-identity as a caregiver?

Knowing your limits and voicing them. Expect trials and challenges as you explore your caregiver role. For example, you may find yourself pushing for change or more support when the person you are caring for isn't ready or only wants you to be their support. This will bring up many difficult emotions. It is important to take care of yourself and be clear on where you can provide support, and where you cannot. Voicing what you can do and what your limits are doesn't stop with the person you are caring for. Sharing them with the health care system, including your family doctor, your care recipient's care team, and friends and family, allows others to know your limits and how to support you best. Also, caregiving is dynamic – expect changes in your limits and boundaries. Don't be afraid to be curious about where your boundaries start and end!

There were times where I found myself wondering if I was doing too little or not speaking up enough. And other times where I felt snowed under and that I was doing too much as a caregiver, especially the longer I was caring for Jeff.

I would circle back to this exercise to help me decide and support my limits:

- *Am I giving myself permission to accept, decline or limit certain activities and responsibilities (related to care and my life)?*
- *What do I want to do, what do I have to do, what am I able to do and what can't I do?*

Understanding and getting consent. The care recipient needs to give consent to a person (typically a caregiver) to have access to their personal health information. There are two main acts in Canada regarding health care consent and patient privacy. Under the Health Care Consent Act, (1994) and the Privacy Personal Health Information Protection Act, 2004 (PHIPA), patient consent is required to share access to their personal health information.

A care recipient (or patient) can consent for their caregiver to have access to their personal health information. This



Check Your Mindset

How we show up as a care partner has a lot to do with our mindset. Shifting our mindset to having an understanding that our needs are as important as the person we care for can be hugely impactful. While it will not remove the peaks and valleys that come with caregiving, it can positively affect the way we show up in our caregiving role (and sometimes can even result in the positive by-product of self-improvement). Here are a few resources to tap into your mindset and energy:

Caregiver Resiliency Check-In Tool:

<https://www.familycaregiversbc.ca/wp-content/uploads/2019/05/Resilience-Strengths-Quiz2.pdf>

Checking-In on How You Are Feeling Self-Assessment:

<https://www.familycaregiversbc.ca/caregiver-self-assessment>

Taking Care of Yourself: Self-Care Strategies for Family and Friend Caregivers Booklet:


<https://www.familycaregiversbc.ca/wp-content/uploads/2020/04/Taking-Care-of-Yourself-Self-Care-for-Caregivers-Booklet.pdf>

What's Your Hook?

We all have times when we “get in our own way” or are “hooked by thoughts” that end up influencing our actions. Here are some questions to bring awareness to how your mindset impacts your caregiving and your own well-being.

- In your caregiver role, how does your mind manage to hook you?
- What sort of things does your mind say to hook you?
- How do you manage to unhook yourself?
- What type of support would be helpful to help you overcome your hooks?





“When people are protecting something truly special to them, they become as strong as they can be.”

— Karen Salmansohn

I had to remind the clinic staff to find my name on file in Jeff's medical record. While Jeff has largely recovered from his brain injury, there are ongoing challenges for him, one of which is organizing his calendar and short-term memory loss. This was something I had to delicately broach with his health care team – to support Jeff to be as independent as possible but also to convey that it was important I was involved. I found it was helpful if I used respectful but clear messaging, “I know Jeff is the patient and we are here to talk about his medical needs, but it isn't just him going through treatment and recovery. Jeff and I work together to manage his recovery plan and it's helpful for me to be part of the care planning.”

consent can range from access to the actual health records to participating in discussions with the provider about the care recipient, giving and receiving information. Regardless of how involved a caregiver is in care, the person receiving care must make their own treatment or care decisions. Care recipients may ask and, in some cases, rely on their caregiver(s) for advice or support in making the decision, but they must make the health care decision themselves.

The reality is that there is no consistent method for a patient or care recipient to provide one-time consent for access to their health information. If the care recipient doesn't want to give consent, then a family caregiver must understand this decision. Another challenge is that in the current system, this process typically needs to be repeated with each provider, and sometimes needs to be re-introduced at subsequent appointments. Consent can be provided verbally, or in writing, and should be documented in the patient's health record.³

Patient and family-centred care is an approach to health care that respects the vital 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.

Here is what worked for Michelle:

I found I still needed to remind Jeff's family doctor and specialist about my part on the care team. Sometimes,

Being organized and prepared. Good information management leads to better care and the ability to make more informed decisions. This includes tracking essential information about the health and well-being of both the person you are caring for and yourself. Here are some tips to get you started:

- ♥ Prepare a medical history of the care recipient and your own (if you are experiencing your own challenges).
- ♥ Organize a binder with pages for their identifying information: name, photo, personal health number, address; and their medical diagnoses and history of appointments and hospital stays; medications and when they are administered; daily routines; preferences; strategies for helping to calm them.
- ♥ Take notes when medical professionals come to speak with you or when you attend appointments, then add these to the binder.
- ♥ Before each medical visit, review your notes and jot down questions for the visit. If questions come up during a visit, note them and ask right away if you can.
- ♥ Find out the names of each provider – nurses, doctors, specialists, techs, and write these down. Different members of the healthcare team may need your support to keep everyone in the loop on care matters.

⁴ UNDERSTANDING HEALTH PRIVACY AND CONSENT IN ONTARIO: A GUIDE FOR CAREGIVERS AND CARE PROVIDERS. (2021).

<https://ontariocaregiver.ca/wp-content/uploads/2021/08/Understanding-health-privacy-and-consent-in-Ontario-a-guide-for-caregivers-and-providers-Aug4.pdf>

“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

Here is what you can do right now and how we can help:

For [emotional support or questions](#) related to caregiving, call our toll-free BC Caregiver Support Line at 1-877-520-3267. We are available 8:30 am - 4:00 pm Monday, Wednesday, Friday and 8:30 am - 7:00 pm Tuesday and Thursday. When you call our support line, we will listen to you and talk with you through 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—see if you qualify](#).

Visit the [Caregiver Learning Center](#). We recognize it can feel overwhelming and time-consuming to sift through websites and links. We have narrowed our focus to provide topics that address the most expressed questions and concerns that we hear from caregivers (e.g., caregiver well-being, financial information, health care navigation and much more). Our caregiver resources aim to: increase your knowledge and skills, build confidence in your caregiving skills, and prevent caregiver burnout.

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

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

Join one of our [family caregiver support groups](#): We are also continually expanding our list of community caregiver support groups around B.C. - [Find one near you](#).



Family Caregiving: Don't do it alone.

Visit your online Caregiver Resource Centre:

www.familycaregiversbc.ca



**Family Caregivers
of British Columbia**

— Let us help —

#6 – 3318 Oak Street, Victoria, BC V8X 1R1

Phone: 250-384-0408

Toll Free: 1-877-520-3267

Email: cgsupport@familycaregiversbc.ca