

CAREGIVER CONNECTION



Family Caregivers
of British Columbia

Let us help

30 YEARS

FALL 2019 | VOL. 33, ISSUE 4

FAMILY CAREGIVER DECISION GUIDE

Dr. Carole A. Robinson, Professor Emeritus, UBC

Most of us will provide care for an ill family member at some point in our lives. Yet, few of us call ourselves "caregivers". Instead, we are wives, husbands, partners, daughters, sons, or sometimes dear friends who simply consider ourselves "family" doing what is important to help those we care about live well, even in sickness. However, providing care can be demanding because it changes with the illness, we often don't know what to expect, and often we're not prepared for the tasks that need doing. Caregiving can also be long-term. Supports and resources are critical but all too often it is difficult to find out what is available and then how to get what we need. Sometimes, we are just too tired to sort it out. So our team at University of British Columbia (UBC) created a unique resource to help family caregivers make decisions over time and give the best care possible: the Family Caregiver Decision Guide.

The Family Caregiver Decision Guide is a national resource for anyone caring for someone with a serious illness. Some people who anticipate providing care (for example, children with aging parents) have also found it helpful to review the guide as preparation. Each family situation is unique. We created the Family Caregiver Decision Guide to help caregivers determine what they need (for example, to know and learn) as well as what

A family caregiver decision guide

Caregiving at home for someone with life limiting illness



In this issue

- Medical Assistance in Dying: An Option in End-of-Life Care
- How to Manage Caregiving Worries
- Meeting Caregivers Where They Are
- Family Caregiver Support Groups

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

supports or resources will enable them to provide the best care, as well as the options if needs for caregiving change.

The Family Caregiver Decision Guide involves a four step process:

1. Think about caregiving now;
2. Think about how caregiving might need to change;
3. Explore available caregiving resources;
4. What are the best options if the needs for caregiving change?

The Family Caregiver Decision Guide can be used in two ways:

1. Online via the following website www.caregiverdecisionguide.ca
2. Download a print version from open.library.ubc.ca/cIRcle/collections/facultyresearchandpublications/52383/items/1.0339902

The guide is best used early in the illness and as things change. If you have a computer and choose to use the website to work through the guide, your answers will be recorded and you can print either one section at a time or the whole guide at the end. It is helpful to see how answers, questions and needs change over time.

How is the guide helpful? It is really important to know that the Family Caregiver Decision

Guide is not meant to be used alone.

Caregivers tell us that thinking through the steps raises many questions. Each caregiver will identify the priority questions that need answers in order to continue providing the



care they want to give. Then it is important to have a conversation with a trusted health care provider – someone who knows them and their care recipient, their situation, and the resources available where they live.

Caregivers need to reach out to those who can provide answers to questions and address concerns, such as Family Caregivers of BC. Through focused conversations, based on working through the guide, caregivers can grow needed knowledge and skills and make informed decisions about how to move forward.

CAREGIVER CONNECTION

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EDITOR'S NOTE

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

Caregivers have many needs in common - no matter what their specific situations. And yet, each caregiver will bring her/his own lens to the information most relevant to them. At Family Caregivers of BC (FCBC) we are listening and learning from those who use our services.

Through calls to our Caregiver Support Line, feedback from Caregiver Support Group Facilitators, input from partnerships, evidence from research and comments from our website, we constantly track a wide variety of topics. In this issue of the Caregiver Connection, our cover article is about an excellent Family Caregiver Decision Guide developed at University of British Columbia by a group of dedicated researchers. Read all about it and better yet, go online and test it out. If you would like to learn more, join us for a webinar about it on Wednesday, **October 2nd at 2pm PST**. Another topic of interest to some caregivers and their care recipients is the new federal legislation that allows Medical Assistance in Dying. Our article on page 4 highlights this very personal choice from the lens of a caregiver. We are also hosting a

webinar to further explore this topic on **Tuesday, November 5th at 6:30pm PST**.

To help you day-to-day, we have included an article about managing worry. This is a popular topic and I think you'll find these tips very helpful. And as part of our goal to profile caregiver support initiatives from around the province, an article from Burnaby Seniors Outreach Society highlights how this community non-profit is responding to the needs of seniors and their caregivers in a variety of ways.

We hope you enjoy this issue and we welcome your suggestions for future ones. Send us your thoughts through the Contact Us link on our website www.familycaregiversbc.ca/contact-us

UPCOMING WEBINARS

Family Caregiver Decision Guide

Dr. Carole Robinson,
Professor Emeritus, UBC

Wednesday October 2nd
2 - 3:30 pm PST

Medical Assistance in Dying

Dr. Rosanne Beuthin, Island
Health

Tuesday, November 5th
6:30 - 8pm PST

Ability411 – Reviewing Technology Aids

Tuesday, November 26th
6:30pm - 8pm PST

MEDICAL ASSISTANCE IN DYING (MAiD): A NEEDED OPTION IN END-OF-LIFE CARE

Margaret Cornish

Reprinted with permission from Island Health Magazine – Summer 2019 Issue

A personal journey

Jim's medical prognosis was clear. Cancer had regained its momentum after intensive chemo and radiation and according to the oncologists, there were no further avenues of treatment. He listened quietly and after a week or so spoke of having accepted that his condition was terminal. Believing radical measures might prolong the time left but result in a declining quality of life, Jim rejected such measures. He was referred to his family physician and to the Victoria Hospice.

Jim (age 71) and I have no children. Both of our extended families live at a considerable distance. During the next month, visits from siblings brought bittersweet closure. An intensely private person, Jim's preference was for "peace and quiet." When asked, he said he was worried about escalating pain and loss of control as the cancer advanced. He didn't complain, express angst or show resistance.

Jim asked his family physician about medical assistance in dying (MAiD). He made the necessary enquiries, speaking directly to one of the three doctors on Vancouver Island licensed (at that time) to administer MAiD. Within days, Jim had the application, a one-page model of simplicity, in which the patient asks for medical assistance in dying. Two neighbours readily agreed to serve as independent witnesses. Not long after, still in the first months after the legislation was passed, Jim received a call from the physician who had agreed to administer MAiD suggesting a home visit. She was both

forthright and compassionate. She reviewed the conditions for MAiD approval and explained the drug choices. She probed Jim on his views about his illness and his state of mind generally—questions that seemed designed to assess his psychological state. She also asked if he realized the certainty that death would occur as a result of the drugs. This elicited a wintry smile and the reply, "I'm a chemist." Jim's practical responses underscored his readiness for medical assistance in dying.

The doctor turned to me as the sole caregiver and family member. Did I agree? Yes, we had long agreed on the principle of individual choice. She noted that the proposed date (12 days hence) was tentative, given the need for a second doctor to review the medical records and give a confirmatory opinion, and to order the rigorously controlled drugs. I did feel a jolt that this was proceeding more quickly than I had expected, but Jim's relief was palpable as he pressed for the earliest possible date.

In the same week, Jim received the initial visit of a Victoria Hospice doctor. From the acceleration of his symptoms, she estimated him at (PPS) Palliative Performance Scale 4, indicating a remaining life of 4–6 weeks. Jim was already experiencing frightening bouts of choking and coughing due to an increasingly restricted throat. She didn't underplay the uncertainty and difficulties of the final stages of throat cancer. She described the hospice focus on symptom and pain management and their success in helping patients remain comfortable, functional and aware.

She spoke of MAiD as one alternative on a continuum of options available in end-of-life care that could be delivered in collaboration with hospice. I was impressed that in the few

Continued on page 6

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 selfcare, 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 where 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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weeks since Jim had made the application (which runs through a different chain of command in the health care system than the hospice network) that senior hospice doctors should have achieved this level of understanding and collaboration with doctors administering MAiD. Perhaps this is not a coincidence. Victoria Hospice has long been considered a leader in end-of-life care in Canada.

I wondered if accelerating death would short-circuit the “spiritual” elements associated with natural death eloquently described in *Final Gifts: Understanding the Special Awareness, Needs and Communication of the Dying*, a book by hospice nurses Maggie Callanan and Patricia Kelley. Beyond physical aspects (not eating, confusion etc.), the book describes intense conversations with people who aren’t present; mental states which cross back and forth between reality and delirium in pursuit of some resolution or reconciliation; anger and fear; efforts to come to terms with one’s life—manifested through symbolic language (e.g. departures, trips).

I observed in Jim’s calm, largely silent, journey the elements described in *Final Gifts*. Some had already occurred. He stopped taking liquid meals although he continued to drink fluids. There was no person or event he was waiting for. He had long ago accepted the verdict of death. There must be a leap between acknowledging death rationally and accepting it in the here and now, but Jim had taken that step. I did sense a growing detachment, a distance—as if he had already taken a separate path while I was still in sight. Several nights before he died, I awoke to find him standing at my bedside looking for something. When I asked what was wrong, he said, “I am trying to find the meaning of life—I thought I might have left it here.” Wry humour or symbolic language?

On the appointed day, Jim (and I) re-signed the MAiD application. Jim lay down beside me

on our bed. Within what seemed seconds of the drug injections Jim was dead—an utterly calm, fully conscious departure.

This ability to accept death as a conscious act may not be for everyone but for patients such as Jim, MAiD eliminates the fear of frantic, final weeks/months of intensive medical management of symptoms when that is not desired nor contributing to quality-of-life.

It provides a critical patient-centred option on a spectrum of end-of-life care that enables a patient to exert some autonomy avoiding the fear and uncertainty of a painful death and to share end-of-life experience with loved ones. Jim felt passionately that MAiD (carefully controlled as it is) should be available to those who seek it. We owe a major debt of gratitude to the doctors and nurse practitioners that administer MAiD, largely from a compassionate commitment to patients’ right to MAiD.

I don’t underestimate the conflicting philosophical and professional demands that MAiD legislation has created for the medical professions. Various factors contribute to the reluctance to administer MAiD, many deeply rooted in professional experience: ethical opposition; concern about potential abuse; addressing conflicting views of family members; and opposition of faith-based institutions, amongst others.

Other critics regard the legislative constraints as depriving many Canadians (whose circumstances do not conform to the rigidly defined terms of the legislation) of access to MAiD. Clinical and institutional as well as individual and family experience with MAiD across Canada should lay the groundwork for

amending and extending the Act.

I believe Jim's experience addresses two major concerns of those who oppose MAiD on ethical grounds. His decision to seek approval for MAiD bore no resemblance to the despair or alienation characteristic of suicide. I was able to provide Jim the same comfort and support as with a natural death. This is the antithesis of the emotional devastation experienced by families and friends following a suicide. Nor did MAiD short-circuit the broader spiritual or symbolic end-of-life

journey that is part of the human experience.

MAiD provides a critical patient-centred option for patients to avoid the increasing pain, fear and uncertainty of the final frantic period, specifically the loss of self-possession associated with highly medicalized end-of-life care. It enables the patient to control the time and circumstances of death. I join those who see MAiD as an enormous step forward for Canada in compassionate care.

Margaret Cornish lives in Victoria, British Columbia

FCBC believes that people have the right to make informed choices about their lives. To support this, we endeavor to bring relevant information to the attention of caregivers, thoughtfully supporting enquiry processes where we can. Articles contributed by others express the opinions of the writers and do not necessarily reflect the views of FCBC.

HOW TO MANAGE CAREGIVING WORRIES

Cassandra Van Dyck

Reprinted with permission from North Shore Community Resources Caregiver Support

Worrying is an unavoidable part of the caregiving journey. As your loved one's health declines, you will inevitably be concerned about lots of things, such as what will happen when you cannot take care of them at home, how your relationship will change, or what they'll be like when their cognition is affected by illness. While it is likely impossible for you to avoid worrying at one time or another, you can learn ways to manage your thoughts so that they do not consume you. Here are some ideas:

Create a worry script. If you are constantly worrying or ruminating on negative worst-case

scenarios, creating a worry script could help you break out of the thought pattern you may feel stuck in. The idea is to write a script of the worst possible outcome for what you're worrying about. Does it sound counter-intuitive? You might be surprised at the results.

Go for a walk. I know what you're thinking... what good will a walk do when you're worrying about not having enough help to meet your loved one's needs? The answer is: a lot of good. Walking, jogging, swimming or any other type of aerobic activity releases endorphins, a feel-good neurotransmitter that might just stop you from thinking negatively. Going for a walk might open your mind up to other possibilities, like asking family members for help. So, the next time you're sitting at home worrying about something, go for a

brisk, 30-minute walk and revisit your worries after.

Accept and release worry. Trying to ignore worries or getting frustrated for thinking about what you're concerned about will not help you feel better. It will likely only create more tension in your body and cloud your thoughts. The next time you feel worried, try just noticing your thoughts, without sinking in to them. Notice them floating around in your head, and then let them go, or set them aside for "worry time."

Set aside a time for worrying. As mentioned, trying to ignore or suppress worries will only make them worse. If you are really concerned about something, try setting a time of day to think about and work through it. Maybe your thoughts are most clear in the morning while drinking your first cup of coffee,

or perhaps it's before you go to sleep when you're settled in to your bed. Set aside this time for worrying, and then work through a plan for sorting through them.

Work through your worry. Coming up with a plan for your concerns is a great way to stop thinking negatively and start thinking proactively. Start small. Take a small concern, and answer these questions. How did you feel before and after?

Please note: if you find that your worries are regularly consuming your thoughts and preventing you from living your life the way that you'd like to be, seeking professional help may be the best way to move forward. Visit your family doctor and let them know how you're feeling. They may suggest a counsellor, psychiatrist, or another path to well-being.

MEETING CAREGIVERS WHERE THEY ARE

Dorothy LeClair

Burnaby Seniors Outreach Service Society (BSOSS) has learned that being adaptable and creative in meeting the needs of caregivers is crucial. We began as Burnaby Seniors Peer Counselling Society. Senior Peer Counselling is the cornerstone upon which our services are built, based on the principles of self-help and personal growth. Senior Peer Counsellors are well trained volunteers who provide one-to-one support, empathy, information and outreach. They meet at a time and place that is convenient for the client. There are times when a caregiver is not able to attend a support group, such as not feeling comfortable leaving their care recipient home alone or not feeling ready as they grapple with their personal challenges. When matched with a peer counsellor we are often able to transition caregivers from one-to-one support

to group support. Recently a caregiver told her peer counsellor she knew others needed her support more than she did. She is now regularly attending a support group as well as our Dementia Friendly Café. One-to-one support can provide that critical safe first step.

Caregiver Support Groups for unpaid caregivers are another essential element in our support services. We recognize the busy lives caregivers lead and offer support groups at various times: Saturday mornings, early evenings, and late evenings. Our facilitators are trained volunteers. While regular attendance at support groups is critical for some caregivers, not everyone is ready for this type of support. Growing our support groups has been challenging.

Our annual Caregiver Expo features guest speakers, vendor tables, and a free lunch. This event has been well received with several hundred people attending. Expo is also an

opportunity to promote our education workshop series. A variety of presenters offer a wide array of workshops from system navigation skills to knowledge of community services. A new “Wellness Series” is being piloted this September with the intent of exposing caregivers to a wide range of approaches to self-care. An art therapist, music therapist, Bollywood Dance instructor and a mindfulness trainer will each offer a 2-hour training on these approaches to self-care. The registration for this series has been swift. We ensure the topics are relevant through the use of evaluations and feedback.

Recognizing that caregivers often experience increased social isolation, we launched two new programs which involve both the caregiver and the care recipient in 2018-2019.

Family and Friend Caregiver Brunch takes place twice a year and a Dementia Friendly Café meets monthly. The Brunch includes food, three speakers and a shared activity. The monthly Dementia Friendly Café has four elements: socializing, information, refreshments, and an hour of singing with a music therapist. The Café model has been an overwhelming success averaging 30 attendees each month.

Caregivers need to be creative and adaptable as they provide compassionate support to their family member or friend. BSOS has learned that when we match these skills in our work we get the best results. Building capacity and strengthening resiliency are the hallmarks of our Caregiver Support programs.

SHARED UNDERSTANDINGS: A SAFE SPACE FOR CAREGIVER SUPPORT

Lacie White, FCBC Caregiver Support

A Caregiver Support Group is where people come together around a mutual experience of caregiving for a family member or friend. Here, a caregiver may give and receive helpful emotional and practical support, empowering them to nurture their own well-being. This is a time for reassurance, where group members realize they are not alone.

The following “shared understandings” or ground rules have emerged from over 30 years of facilitating support groups for caregivers:

- **We respect confidentiality** – by NOT sharing personal details of other caregivers’ lives and experiences, outside of the group setting. However, information and resources learned about
- may be used or shared with those who may benefit outside the group.
- **We are non-judgmental** – remembering that every individual and situation is different, we honour each caregivers’ own experiences, just as they are. There is no right or wrong path, including having and expressing strong emotions, as long as they are shared in a respectful manner.
- **We share our time together** – making sure everyone has an opportunity to speak (or remain quiet/silent) to their own comfort level.
- **We listen respectfully** – focusing on each person as they share. We avoid side conversations. We turn our cellphones off or switch to silent and, if needed, leave the room to take a call.
- **We do not give advice** – instead, with

permission, we can share ideas from what we have learned from personal experience. We know our own personal experiences, yet we do not know what is best for anyone else.

- **We accept the range of human expression** – silence, laughter and tears are ok.
- **We speak using 'I', not 'you' language** – since the focus of each participant's sharing is about one's own personal experience, rather than another person's life and situation.

Having a group (co)facilitator helps to embrace the shared understanding; in this model, no one person is the "expert" – the group is the source of lived experience. Our peer group model is based on volunteer facilitators, while others may use paid staff. The topics of the group are chosen by the group members. The facilitator

can help spark conversation, encourage acting in accordance with the group's shared goals and understandings, keep track of time, and overall, help the group toward a safe and comfortable environment for everyone.

It can be helpful for groups to review the shared understandings at the beginning of each meeting. Feel free to edit this to suit your group and adapt it over time.

Caregiver Support Group Facilitator Training

Join a free training session in Greater Victoria in November 2019.

For more information please connect with monicalewis@familycaregiversbc.ca



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

Support groups can be found in the following BC communities:

Burnaby
Campbell River
Chemainus
Comox

Coquitlam
Cowichan
Cranbrook
Creston
Delta
Duncan
Fernie
Gabriola Island
Golden

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
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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)

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 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".

BC Palliative Care Benefits

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

BC Seniors Guide

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

1-877- 952-3181

Crisis Centre BC

crisiscentre.bc.ca/contact-us

1-800-SUICIDE (1-800-784-2433)

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www.familycaregiversbc.ca

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Find Support BC

findsupportbc.com

HealthLink BC

www.healthlinkbc.ca

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

Here to Help

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.

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