

# A family caregiver decision guide



Caregiving at home for someone  
with life-limiting illness



# Things change and this decision guide can be used over and over.

Here's a place to keep track when I use the guide.

**This guide is the property of the \_\_\_\_\_ family.**

First completed on this date: \_\_\_\_\_.

Reviewed a second time on this date: \_\_\_\_\_.

Reviewed a third time on this date: \_\_\_\_\_.

Last completed on this date: \_\_\_\_\_.

*(Some people find it helpful to use a different color each time they complete the guide.)*

You may reproduce the Family Caregiver Decision Guide for your own use (not for sale or distribution without permission). For further information regarding this guide contact Dr. Carole Robinson at [carole.robinson@ubc.ca](mailto:carole.robinson@ubc.ca).

## ACKNOWLEDGEMENTS

*The team sincerely thanks all the families who participated in the research to create this guide. We would also like to thank Natalia Polchenko, Laura Bissell, and Janelle Zerr for their valuable contributions. Funding support for the guide was provided by Interior Health in partnership with the Institute for Healthy Living and Chronic Disease Prevention at The University of British Columbia Okanagan campus, as well as the British Columbia Cancer Foundation.*

## SUGGESTED CITATION

Robinson, C.A., Pesut, B., & Bottorff, J.L. (2015). *A family caregiver decision guide*. Kelowna, BC: University of British Columbia.



**THE UNIVERSITY  
OF BRITISH COLUMBIA**

ISBN: 978-0-88865-158-7  
© Robinson, C.A., Pesut, B., Bottorff, J.L. 2015

## This decision guide is for me, if:

- My family member is living with a life-limiting illness
- I would like to plan for possible changes in needs for caregiving for my family member.

Providing care for a family member is a process that often changes, sometimes quite suddenly. You may provide more care over time – alone, or with help from others. Careful planning allows you to care for your family member at home for as long as possible if you choose to do so. This guide will help you with this plan.

### You will be guided through four steps to help you with your decision planning:



*Not all parts of this guide will apply to you today. Focus on the parts that are important to you **right now** and finish the other parts that may be more relevant to you later on. It may be useful to complete this guide one step at a time or over several days. Revisit it when needs for caregiving change.*

*Once you have completed this guide, talk it over with a health care provider to answer any questions or needs that may arise. Some people may want to complete the guide with a nurse or volunteer.*

1

## Think about my caregiving situation *now*.

### How am I managing with...

I DO NOT  
NEED  
HELP

I COULD  
USE SOME  
HELP

Home maintenance:

- Inside

☐
☐

- Outside

☐
☐

Car maintenance

☐
☐

Grocery shopping

☐
☐

Cooking

☐
☐

Taking care of pets

☐
☐

Home changes for safety and convenience (e.g., wheelchair ramps, grab bars in the bathroom etc.)

☐
☐

Getting special equipment (e.g., walker, hospital bed, commode, wheelchair)

☐
☐

Personal care of my family member:

- Bathing

☐
☐

- Toileting

☐
☐

- Dressing

☐
☐

- Transferring in and out of bed

☐
☐

- Managing incontinence of bowel and/or bladder

☐
☐

- Wound care

☐
☐

*Continued on next page...*



*Continued from previous page...*

**I DO NOT  
NEED  
HELP**

**I COULD  
USE SOME  
HELP**

My family member's :

- Pain control
- Symptom management (e.g., constipation, nausea and vomiting, breathlessness, confusion, trouble swallowing)
- Medications (e.g., giving and keeping a record)
- Emotional needs
- Spiritual needs
- Transportation to and from healthcare appointments

Knowing the signs and symptoms of a problem that requires medical attention

Helping my family member stay involved in meaningful activities

Helping my family member stay active

☐
☐
☐
☐
☐
☐
☐
☐
☐
☐
☐
☐
☐
☐
☐
☐
☐
☐

## How confident am I with...

I AM  
OKAY  
NOW

I COULD  
USE SOME  
HELP

I MAY  
NEED HELP  
IN FUTURE

Understanding the illness now

☐
☐
☐

Understanding how the illness is likely to change over time

☐
☐
☐

Understanding changes that might require medical attention

☐
☐
☐

Understanding the goals of treatment

☐
☐
☐

Recognizing when end of life is approaching

☐
☐
☐

Talking with my family member about the illness, how it may change, and plans for care

☐
☐
☐

Understanding my family member's wishes for care:

• Now

☐
☐
☐

• Towards end-of-life (e.g., goals of care, advance care plan, resuscitation orders)

☐
☐
☐

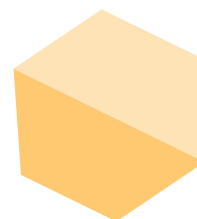
## Overall, how well am I managing caregiving now?

Please, place an "X" on the line to show how well you are managing:

Poorly



Very well





**What might be helpful to maintain my health so that I can provide the best care for my family member?**

Financial support (e.g., income replacement, palliative benefits, employee assistance)

**I AM  
DOING  
OKAY**

**I COULD  
USE MORE  
OF THIS**

☐
☐

Legal support (e.g., representation agreement for health care decision making, Power of Attorney, will)

☐
☐

Emotional support (e.g., counselling)

☐
☐

Religious or spiritual support

☐
☐

Getting some time for myself

☐
☐

Breaks from caregiving (respite):

- In the home

☐
☐

- Outside the home

☐
☐

Doing meaningful things

☐
☐

Keeping active

☐
☐

Other (specify): \_\_\_\_\_



*"It's important to think about how your caregiving will change, because it will! Being a caregiver...you have to make choices...it's challenging. And when needs change over time, it's important to revisit your options. Planning in advance is a good idea. But sometimes you can't predict what will happen. As things change it is important to ask yourself if you can maintain the care you want to give."*

*(Family caregiver)*

2

**Think about how caregiving might need to change either *now* or *in the future*.**

**Have I thought about the choices I might have to make?**

- ☐ Yes
- ☐ No

**What would tell me that I cannot keep caregiving at home any longer?** *Tick all that apply.*

- ☐ Cannot keep up with important tasks
- ☐ My own health is worsening
- ☐ My family member's pain becomes unmanageable at home
- ☐ My family member's symptoms are getting unmanageable at home
- ☐ Exhaustion
- ☐ Mixed emotions about living in the home after death
- ☐ Other (specify): \_\_\_\_\_

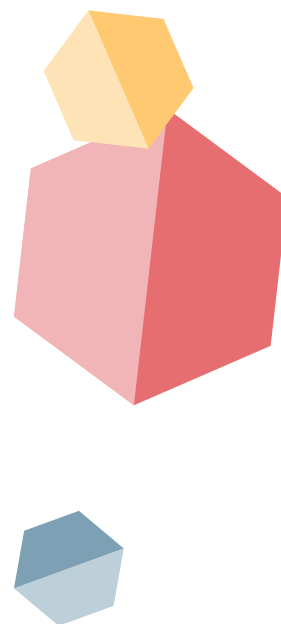
**What things influence me when it comes to making choices about caregiving for my family member?** *Tick all that apply.*

- ☐ Beliefs about what is right
- ☐ Desire to spend time with my family member
- ☐ Lack of information about options, pros and cons
- ☐ Views of other family members about the care that is needed
- ☐ Available support from family or friends
- ☐ Available support from healthcare providers
- ☐ Lack of understanding about how the illness will go
- ☐ Comfort and privacy of home
- ☐ My family member's wishes to stay at home
- ☐ My family member's wishes to be cared for by me
- ☐ Promise for family member to stay at home until death
- ☐ Feeling pressure from others
- ☐ Other (specify): \_\_\_\_\_



## What things influence my family member when it comes to making choices about their care? *Tick all that apply.*

- ☐ Beliefs about what is right
- ☐ Desire to spend time with family
- ☐ Lack of information about options, pros and cons
- ☐ Feeling pressure from others
- ☐ Available support from family or friends
- ☐ Available support from healthcare providers
- ☐ Lack of understanding about how the illness will go
- ☐ Comfort and privacy of home
- ☐ Desire to stay at home
- ☐ Desire to be cared for by me
- ☐ Desire not to be a burden
- ☐ Other (specify): \_\_\_\_\_
- ☐ I am unclear about what is most important to them



## Who else is involved in caregiving for my family member?

WHO IS THIS PERSON (NAME)?

WHAT ROLE DOES THIS PERSON PLAY IN PROVIDING CARE?

|          |       |
|----------|-------|
| 1. _____ | _____ |
| 2. _____ | _____ |
| 3. _____ | _____ |
| 4. _____ | _____ |
| 5. _____ | _____ |

## Explore caregiving options *in my area*. Do I know what supports are available to *me*?



### Are the following resources available in my area?

|                                                       | YES                   | NO                    | DON'T KNOW            |
|-------------------------------------------------------|-----------------------|-----------------------|-----------------------|
| Food and meal services                                | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Pet care services                                     | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Housekeeping services                                 | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Recreation programs                                   | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Medical equipment & supplies                          | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Transportation                                        | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Support for specific conditions (e.g., cancer)        | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Programs to give me a break from caregiving           | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Volunteers (e.g., hospice or community services)      | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Physiotherapy                                         | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Medication management and delivery (e.g., pharmacies) | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Personal care for my family member                    | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Caregiver support (e.g., groups, counselling)         | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |



4

## What are my *best options* if the needs for caregiving change?

**Respite\*** is a short period of rest and relief for caregivers. Respite can be provided in the community through Adult Day Services or in a residential care facility on a short-term basis or in a hospice.

**Health Care Facility\*\*** could mean a hospital, long term care facility, palliative care facility, or hospice.

### How do I feel about these caregiving options?

#### HOME WITH INCREASED RESOURCES

I really dislike this option 1 2 3 4 5 I really like this option

My reasons:

#### HOME WITH RESPITE\* AWAY FROM HOME

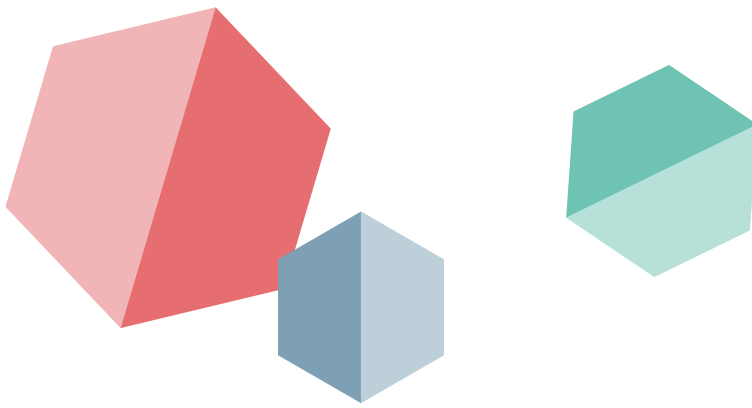
I really dislike this option 1 2 3 4 5 I really like this option

My reasons:

#### HEALTH CARE FACILITY\*\*

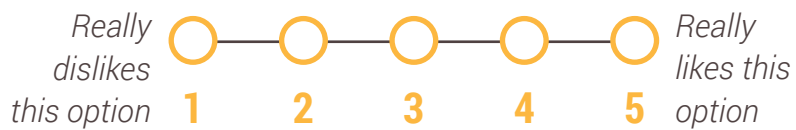
I really dislike this option 1 2 3 4 5 I really like this option

My reasons:



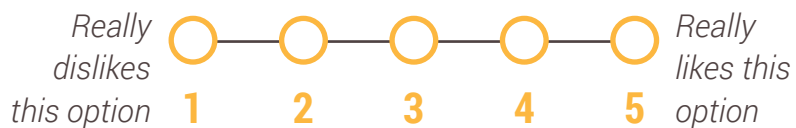
## How does my family member feel about these caregiving options?

### HOME WITH INCREASED RESOURCES



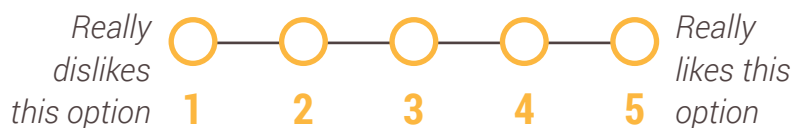
Their reasons:

### HOME WITH RESPITE\* AWAY FROM HOME



Their reasons:

### HEALTH CARE FACILITY\*\*



Their reasons:

## Considering everything I know... What is my best option for caregiving now?

- ☐ No change
- ☐ Home with increased resources
- ☐ Home with respite away from home
- ☐ Hospital
- ☐ Care Facility
- ☐ Palliative Care
- ☐ Hospice
- ☐ Other (specify):

## Considering everything I know... What is my best option if the needs for caregiving change?

- ☐ Home with increased resources
- ☐ Home with respite away from home
- ☐ Hospital
- ☐ Care Facility
- ☐ Palliative Care
- ☐ Hospice
- ☐ Other (specify):

## Ask myself.....

What do I need to do now so I can continue caregiving?

|  |
|--|
|  |
|  |
|  |
|  |
|  |
|  |
|  |
|  |
|  |

What do I need to do now to prepare for future changes in caregiving?

|  |
|--|
|  |
|  |
|  |
|  |
|  |
|  |
|  |
|  |
|  |
|  |

**What questions do I have for a family doctor or other health care professional (e.g., community or palliative nurse) about caring at home?**

|  |
|--|
|  |
|  |
|  |
|  |
|  |
|  |
|  |
|  |
|  |
|  |

**What questions do I have for a family doctor or other health care professional about alternative places of care (e.g., Health Care Facility)?**

|  |
|--|
|  |
|  |
|  |
|  |
|  |
|  |
|  |
|  |
|  |
|  |

# Contact Information

## Who can I contact for help?

Doctors:

Health Care Agencies (e.g., home care, community nursing, hospice or palliative care, Red Cross equipment loan services, Meals on Wheels):

Family:

Friends:

Religious or Spiritual Leader:

Lawyer or Notary, Accountant, Financial Advisor:

Bank Contact, Branch and Account Numbers:

Other Important Contacts(specify):

## Notes

[illegible]

## Resources

| ADVANCE CARE PLANNING                                                                                             |  |
|-------------------------------------------------------------------------------------------------------------------|--|
| Speak Up <a href="http://www.advancecareplanning.ca">www.advancecareplanning.ca</a>                               |  |
| Exit: The Life and Death Planner <a href="http://www.theexitplanner.weebly.com">www.theexitplanner.weebly.com</a> |  |

| FAMILY CAREGIVER RESOURCES                                                                      |                |
|-------------------------------------------------------------------------------------------------|----------------|
| Aging Parents Canada <a href="http://www.agingparentscanada.ca">www.agingparentscanada.ca</a>   |                |
| Caregiving.com <a href="http://www.caregiving.com">www.caregiving.com</a>                       |                |
| The Family Caregiver <a href="http://www.thefamilycaregiver.com">www.thefamilycaregiver.com</a> | 1-800-209-4810 |
| Canadian Mental Health Association <a href="http://www.cmha.ca">www.cmha.ca</a>                 |                |

| HOSPICE/PALLIATIVE CARE                                                                                                                                                                                                                                                                                                                                                                              |                |
|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------|
| American College of Physicians Home Care Guide for Advanced Cancer<br><a href="http://www.acponline.org/patients_families/end_of_life_issues/">www.acponline.org/patients_families/end_of_life_issues/</a><br><ul style="list-style-type: none"> <li>US site that has valuable resources for family, friends and hospice workers when caring for individuals with advanced cancer at home</li> </ul> |                |
| Canadian Virtual Hospice <a href="http://www.virtualhospice.ca">www.virtualhospice.ca</a>                                                                                                                                                                                                                                                                                                            |                |
| Canadian Hospice Palliative Care Association <a href="http://www.chpca.net">www.chpca.net</a><br><ul style="list-style-type: none"> <li>Select 'Family Caregiver' tab</li> </ul>                                                                                                                                                                                                                     | 1-800-668-2785 |
| Family Caregiving for People at the End of Life <a href="http://www.eolcaregiver.com">www.eolcaregiver.com</a><br><ul style="list-style-type: none"> <li>There is a great resource link on the home page</li> </ul>                                                                                                                                                                                  |                |
| Family Hospice Care <a href="http://www.legacies.ca">www.legacies.ca</a>                                                                                                                                                                                                                                                                                                                             |                |
| Victoria Hospice <a href="http://www.victoriahospice.org">www.victoriahospice.org</a><br><ul style="list-style-type: none"> <li>Select the 'How we can help you' tab</li> </ul>                                                                                                                                                                                                                      |                |

| GOVERNMENT ASSISTANCE                                                                                                                                                                                                     |               |
|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------|
| Canada Benefits <b><a href="http://www.canadabenefits.gc.ca">www.canadabenefits.gc.ca</a></b><br><ul style="list-style-type: none"> <li>Go to the middle section under 'Life Events' then 'Dealing with death'</li> </ul> |               |
| Health Canada – Palliative and End-of-Life Care<br><b><a href="http://www.hc-sc.gc.ca/hcs-sss/palliat/index-eng.php">www.hc-sc.gc.ca/hcs-sss/palliat/index-eng.php</a></b>                                                |               |
| Employment Insurance (EI) Compassionate Care Benefits<br><b><a href="http://www.servicecanada.gc.ca/eng/ei/types/compassionate_care.shtml">www.servicecanada.gc.ca/eng/ei/types/compassionate_care.shtml</a></b>          | 1-800-622-623 |

| GRIEF AND BEREAVEMENT SUPPORT                                                                                                                                                                                                                                                                           |                |
|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------|
| After Caregiving Ends <b><a href="http://www.caregiving.com">www.caregiving.com</a></b><br><ul style="list-style-type: none"> <li>Under 'Blogs' tab then 'After Caregiving Ends'</li> </ul>                                                                                                             |                |
| Bereavement Self-Help Resources<br><b><a href="http://www.bccancer.bc.ca/our-services/services/library/recommended-websites/living-with-cancer-websites/grief-websites">http://www.bccancer.bc.ca/our-services/services/library/recommended-websites/living-with-cancer-websites/grief-websites</a></b> |                |
| Compassion Books <b><a href="http://www.compassionbooks.com">www.compassionbooks.com</a></b>                                                                                                                                                                                                            | 1-828-675-5909 |
| GriefNet <b><a href="http://www.griefnet.org">www.griefnet.org</a></b>                                                                                                                                                                                                                                  |                |
| Journey of Hearts <b><a href="http://www.journeyofhearts.org">www.journeyofhearts.org</a></b>                                                                                                                                                                                                           |                |
| Kidsaid– 2 Kids, 4 Kids, by Kids <b><a href="http://www.kidsaid.com">www.kidsaid.com</a></b>                                                                                                                                                                                                            |                |

| INFORMATION ON SPECIFIC ILLNESSES                                                                                                                                                                                                                                  |                                      |
|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------|
| ALS Society of Canada <b><a href="http://www.als.ca">www.als.ca</a></b>                                                                                                                                                                                            | 1-800-267-4257                       |
| Alzheimer Society of Canada <b><a href="http://www.alzheimer.ca">www.alzheimer.ca</a></b>                                                                                                                                                                          | 1-800-616-8816                       |
| Canadian AIDS Society <b><a href="http://www.cdnaids.ca">www.cdnaids.ca</a></b>                                                                                                                                                                                    | 1-800-499-1986                       |
| Canadian Cancer Society <b><a href="http://www.cancer.ca">www.cancer.ca</a></b>                                                                                                                                                                                    | 1-888-939-3333                       |
| Cancerview <b><a href="http://www.cancerview.ca">www.cancerview.ca</a></b><br><ul style="list-style-type: none"> <li>Link to 'Resources for Patients and Families' on the home page</li> <li>Excellent Caregiver video link in 'The Truth of It' series</li> </ul> | 1-877-360-1665                       |
| Cancer Chat Canada <b><a href="http://www.cancerchatcanada.ca">www.cancerchatcanada.ca</a></b>                                                                                                                                                                     | 1-877-547-3777 ext. 645234           |
| Canadian Diabetes Association <b><a href="http://www.diabetes.ca">www.diabetes.ca</a></b>                                                                                                                                                                          |                                      |
| Canadian Lung Association <b><a href="http://www.lung.ca">www.lung.ca</a></b><br><ul style="list-style-type: none"> <li>Education and resource materials under 'Lung Health' tab</li> </ul>                                                                        |                                      |
| Heart and Stroke Foundation of Canada <b><a href="http://www.heartandstroke.ca">www.heartandstroke.ca</a></b>                                                                                                                                                      |                                      |
| Kidney Foundation of Canada <b><a href="http://www.kidney.ca">www.kidney.ca</a></b>                                                                                                                                                                                | 1-800-361-7494                       |
| Leukemia and Lymphoma Society of Canada <b><a href="http://www.LLS.org/canada">www.LLS.org/canada</a></b>                                                                                                                                                          | 1-800-955-4572                       |
| National Cancer Institute <b><a href="http://www.cancer.gov">www.cancer.gov</a></b><br><ul style="list-style-type: none"> <li>US site, but provides information internationally as well.</li> </ul>                                                                | 1-800-422-6237<br>Mon-Fri 8am-8pm ET |

**For more information regarding this guide:**

Contact Dr. Carole Robinson at [carole.robinson@ubc.ca](mailto:carole.robinson@ubc.ca)



**THE UNIVERSITY  
OF BRITISH COLUMBIA**

