



# HOW TO SUPPORT A FAMILY CAREGIVER

This booklet was created to help caregivers of those with serious or life-threatening illness to get support from friends and family with this challenging and rewarding job. Often people who are caregiving at home are very busy. Friends and family may wish they could help, but simply do not know what they can do. It has been our experience that a lot of time and energy can be taken up in organizing people to help. We hope this booklet can be useful to encourage support in a way that is most helpful to the caregiver. This booklet came about as a result of a study on Family Caregiver Coping funded by the Canadian Cancer Society. All quotes are from study participants.

*I would suggest to caregivers taking up what [helps] you can take up. Because people want to help and they want to help because they can't cure the cancer. They want to help and they don't know what to do. So I suggest taking it up [the help]. It's easier for me to ask my family, but people have brought over muffins and casserole dishes. It does help in a way, right? I suggest that they have some kind of network. If they don't have their family, find some friends that will help.*

Study Participant

## Contents

INTRODUCTION.....	2
WHAT YOU CAN DO TO HELP: LISTEN.....	2
THINGS TO THINK ABOUT .....	3
OFFER HELP .....	4
SUPPORT OF THE BEREAVED CAREGIVER.....	5
RESOURCES.....	6
ACKNOWLEDGEMENTS.....	6

*Caregiving is a gift you can give to the person who's dying. It's the last gift you can give them. And maybe if [people can] see it that way, instead of a terrible chore (although it is that as well). But again it's the most positive way to say that you will take a terrible thing and do the best you can with it. You will make someone's life easier when it's so hard...*

Study Participant

## **Introduction**

When someone has a serious or life threatening illness he or she often relies on family or friends to provide support through the important role of caregiving at home. Family caregivers are often responsible for the physical and emotional care of the patient, running the home, as well as organizing and coordinating the necessary health care services. In order for the caregiver to continue providing care in the home, they too need support. The focus is usually on the needs of one being cared for, and not on the caregivers. This can distract the caregiver from acknowledging their own need for support. Because the caregiving experience changes from day to day, so do the needs of the caregiver. When you have a friend or relative who is caring for someone who is seriously ill, there are ways in which you can help support them in this role. We have provided some practical suggestions in this booklet that can help you to understand some of needs of the caregiver. This can give you an opportunity to be pro-active in your supporting role.

### **LISTEN**

At times the caregiver needs to talk to someone about what they are experiencing. They may also need to talk about everyday events to feel normal and connected to the outside world. At these times you can support the caregiver by simply listening to them.

It may be helpful to remember that we don't always recognize how we sound when talking to other people. Sometimes statements sound judgmental. It may be easy to believe that you might do things differently from how the caregiver does them, but it is important to positively support the caregiver's efforts. Being non-judgmental goes a long way in offering support.

It is also important to remember that emotions change over time, from day to day and even from hour to hour. The feelings the caregiver is experiencing may not be typical of them nor what you might expect. When you are listening to the caregiver, it helps if you are accepting of their feelings and understand their need to express themselves to help cope with their daily tasks of providing care.

*I think it is important for caregivers to have people to talk to. I have three girlfriends and when I'm feeling [a certain way], I know which one to call to get what I need. And so I think that's important to be able to do that, to just get it out and they understand that you're just getting it out, not take it too literally. Other than having counseling, sometimes you need to talk to someone. So I have that and I think that's very important.*

Study Participant

## THINGS TO THINK ABOUT

Remember that caregiving brings a variety of responsibilities and the caregiver is balancing multiple needs and priorities. Therefore, it is important that the caregiver's wishes regarding caregiving, receiving help, and visiting be respected.

There is diversity in how different cultures and religions approach illness and caregiving. The beliefs of the caregiver and patient may be different from your own.

Information is preferred to advice and if you have experience as a caregiver it may be helpful to share your wisdom. Instead of telling the caregiver how to do something, you might say: "What worked for me was..." or "Here are a few things you might want to think about..."

Offer to do things with, not always for, the caregiver.

Some caregivers may encounter feelings of guilt over the use of respite services or taking a break from caregiving, and may require your support regarding their decisions.

Caregiving is a journey - it may be long and it may be frustrating at times, but it is often rewarding.



## OFFER HELP

Some caregivers put on a brave face and won't ask for help. Others don't have the time or energy to tell you how you can help them. By offering concrete and specific help and by being prepared to follow through with your offer, you can support the caregiver in their daily tasks. Some ways in which you can be pro-active about offering help include:

- ☞ Check with the caregiver before doing things to make sure it's OK.
- ☞ It's not the big things that help, it's the little things that make the difference.
- ☞ Phone the caregiver, don't wait for them to contact you.
- ☞ Call before you go over to make sure it is OK to visit. The time may not be appropriate and too many people can be overwhelming for both the caregiver and the patient.
- ☞ Let the caregiver know you are willing to come when needed and be available by phone.
- ☞ Only offer help if you can give it (don't offer to fix the shower if you don't know how).
- ☞ Give information, but not advice.
- ☞ Act, don't react: if the grass needs mowing, do it.
- ☞ Prepare meals that can go in the freezer or bake muffins and cookies.
- ☞ Offer to take the caregiver with you for grocery shopping or errands, or offer to do this for them.
- ☞ Offer to take the caregiver out for a short break, such as going for a walk or a car ride, or going to the library.
- ☞ Take the caregiver out for lunch, or bring lunch in.
- ☞ Assist the caregiver in exploring community resources or even attending a support meeting with them.
- ☞ Provide information regarding resources available in the community.
- ☞ Drop a note or send an email enquiring about how the caregiver is doing as well as how the patient is doing.
- ☞ Help with household tasks, do the laundry or the dishes, make the beds.
- ☞ Let the caregiver know you are sending positive energy their way and that you are thinking of them.
- ☞ Maintain your friendships and connections with them.

**Be flexible with how you offer support.**

*I have a number of friends who have offered solace in a lot of ways. They'll come over for a visit and I feel that there are a number of people who I can call if I need some assistance.*

Study Participant



## Support of the Bereaved Caregiver

Some caregivers find that after caregiving is over, friends retreat due to their discomfort with death. Maintaining friendships and connections are as important in this phase as during active caregiving.

Sometimes caregivers feel they need permission to start a new life with a focus on their needs. Being non-judgmental and supporting their decisions will help the caregiver during this challenging time.

You can share what support services are available and go with them to support groups. Continuing to help as you have in the past will benefit the caregiver, help maintain friendship and connections and may help your own grieving process. It is important to acknowledge and attend to your own feelings of grief as well.

*I found that getting back into a social scene, it was very hard at first. Every time I went out and I saw someone I knew, I'd be gone. But when I saw [my friends] two or three times, then it wasn't so bad. You can try and join groups or something. Certainly I think the hiking or the walking groups are marvellous. I found too that I'm getting back to having people in now and again, or if they just drop in for a short visit, never mind getting food and so on, I can just sit down and have a little chat. And I've been having maybe one couple at a time so that they get used to, coming to see me on my own, and I get used to going to their place, and seeing them.*

Study Participant

## Resources

Canadian Virtual Hospice: [www.virtualhospice.ca](http://www.virtualhospice.ca)

BC Cancer Agency/Public Info: [www.bccancer.bc.ca](http://www.bccancer.bc.ca)

Canadian Cancer Society: [www.cancer.ca](http://www.cancer.ca)

Family Caregiver Network Society: [www.fcns-caregiving.org](http://www.fcns-caregiving.org)

Seniors Serving Seniors: [www.seniorsservingseniors.bc.ca](http://www.seniorsservingseniors.bc.ca)



*Just try and create joy. Create joy for the loved one that's suffering and also the caregiver, because they are totally living that illness. That illness has engulfed both of them, or the family. If in some small way you can create joy, whether it be going for a ride in a car and not having to drive and make decisions where to go... just the smallest little thing. And for the caregiver to be an effective caregiver, they have to have a place where they can... a place for them to renew their self, their springs, their spring of life.*

Study Participant

The information provided here is from the Family Caregiving Coping in End-of-Life Cancer Care Study, funded by the Canadian Cancer Society through the National Cancer Institute of Canada.

*Principal Investigator: Kelli Stajduhar, RN, PhD*

*Co-Investigators: Gillian Fyles, MD and Doris Barwich, MD*

This booklet was developed by:

Jennifer Duda (3rd year nursing student),

Meredith Grey (4th year nursing student) and

Wanda Martin, Project Coordinator,

along with help from the Friends of the Centre on Aging, University of Victoria.

January, 2007.

