The Complete Caregiver Support Guide
A Reproducible Workbook for Groups and Individuals
by Ester R. A. Leutenberg & Carroll Morris
with Kathy Khalsa, otr/l
Illustrated by Amy L. Brodsky, lisw-s
We dedicate this book to our loved ones for whom we have been caregivers.

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# The Complete Caregiver Support Guide

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Support Group Openers & Closers

The pages in this chapter are to be used as a launching point for a support group or as a closing thought. They can be read by the facilitator, volunteers or each person reading a line or two, going around the room.

Want Ad for a Caregiver

WANTED:

Mother Theresa clone willing to relocate. Must be able to hear angry words without taking them personally; to be with other people’s problems without getting weighed down; and to deal with unpleasant realities with patience, skill and humor. A plus if willing to cook, clean, manage finances, drive and get by on catnaps. Understanding of pain, grief and loss is a must. Salary will not be commensurate with duties performed; however, blessings will accumulate in heavenly savings account. Benefits include meaningful employment, knowing you made a difference, and gratitude and love from the family and care-receiver. Vacations are possible only when you can replace yourself.

~Carroll Morris
Post this Bill of Rights in your bedroom and read it each morning.

I have the right to be told and relay the truth to the immediate family.

I have the right to be upset when I receive bad news about my care-receiver.

I have the right to talk about my care-receiver’s illness when appropriate, or not.

I have the right to give constructive feedback, in a calm assertive way to a medical professional or establishment that is caring for my care-receiver.

I have the right to disagree with my care-receiver, even though he or she is ill.

I have the right to not accept on any attempt by my care-receiver (either conscious or unconscious) to manipulate me through guilt, anger or depression.

I have the right to engage outside help even though my care-receiver would prefer only me.

I have the right to look after my own needs as well as my care-receiver’s needs. This is not an act of selfishness. It will increase my ability to care for him or her.

I have the right to enjoy my good health and do what it takes to keep it that way.

I have the right to recognize the limits of my own endurance and strength.

I have the right to get help for myself if I need to.

I have the right to receive consideration, affection, forgiveness, and acceptance from my care-receiver, when he or she is capable, providing I offer the same qualities.

I have the right to be free of verbal, emotional or physical abuse from my care-receiver or my care-receiver’s family.

I have the right to feel what I feel, when I feel it.

I have the right to cry.

I have the right to be angry and depressed and to express difficult feelings occasionally.

I have the right to feel frustrated and/or angry and without feelings of guilt.

I have the right to seek humor in difficult situations.

I have the right to do some things just for myself.

I have the right to protect my individuality and make a life for myself that will sustain me for the time when my care-receiver no longer needs my full-time help.

I have the right to long for normalcy.
Caregiver’s Bill of Rights

Read this with your care-receiver and then post it in your care-receiver’s bedroom or main living area.

I have the right to be told the truth about my condition.
I have the right to be told if anything changes with my condition.
I have the right to ask questions of my health-care professional.
I have the right to have an opinion about my health care.
I have the right to talk to anyone about my condition.
I have the right to be treated as a person who can make my own decisions.
I have the right to decide when and whom to ask for help in making decisions.
I have the right to give feedback to the medical community in an assertive way.
I have the right to give feedback to my caregivers in an forthright, but loving way.
I have the right to be treated with courtesy and respect, and to give that back in return.
I have the right to ask for help with the things I cannot do.
I have the right to be free of pain, if that is my choice.
I have the right to be free of verbal or physical abuse.
I have the right to respectful treatment of my property.
I have the right to assertively speak my mind and share my feelings.
I have the right to be angry at people I love and work it out with them in a respectful way.
I have the right to cry.
I have the right to be frustrated.
I have the right to feel bad if I receive bad news.
I have the right to not allow my illness/disease to control every moment of my life.
I have the right to think about other things besides my illness/disease.
I have the right to be hopeful.
I have the right to long for normalcy.
I have the right to wish for a miracle.

This handout can be discussed in a caregiver’s meeting to evaluate how each member is respecting these rights.
Ask yourself these questions periodically to stay aware of your current needs. Caregivers may also wish to complete this handout periodically with their care-receiver. You might want your care-receiver to respond to these questions, also. Discuss your answers.