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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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.
How Am I Doing Right Now?
For the Caregiver and the Care-Receiver

What am I thinking right now?

_____________________________________________________________________________________

What am I feeling right now?

_____________________________________________________________________________________

On a scale of 1-10, how much stress am I feeling? (1 being the least)

_____________________________________________________________________________________

What am I doing to help myself?

_____________________________________________________________________________________

What more can I do to help myself?

_____________________________________________________________________________________

What do I need the most right now?

_____________________________________________________________________________________

Whom can I call on for support?

_____________________________________________________________________________________

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.