

CAREGIVER SURVIVAL RULES

Developed and Adapted by Mike Martelli, PhD

1. Caretakers can not take care of anyone if they BURN OUT from not taking care of themselves. For starters, try scheduling one half day per week off for rest and relaxation, in some form of recreation that *does not* involve treating, helping, caretaking, or being responsible for anyone else, building to one full and one-half day, and moving toward caretaking of no more than 40 hrs/week

2. It is in the patient and caretaker's best interest to learn to easily & openly ask others for help!

3. At least some of the caretaker-patient (usually husband-wife) interaction must include non-caretaking activities - i.e. allowing interaction in the patient's areas of residual strengths and competencies - especially for leisure activities.

(RX: Perform an inventory of every enjoyable activity ever tried or thought of and start planning and experimenting - the more non-caretaking activities engaged in, the stronger the relationship can become.

4. Be a "Mirror" and not a "Sponge".

- ***Sponging is absorbing another persons negative emotions (e.g., anger) and reacting to them with similar negative emotions. It is catching the other persons negative emotions and allowing them to control your emotions and reactions.***
- ***Mirroring is the process of simply reflecting back another person's negative emotions (e.g., "You are angry that I did not come when you first called...Hmm"), without emotional reaction, without obligation to respond emotionally, or to agree or disagree, and without "catching" the emotion. By its nature, mirroring involves a slow, deliberate and open look at the other person statements, and prevents escalation of emotions, allowing you to control your emotions by not reacting. It allows under-reacting or keeping a cool head to help calm the situation, and prevents you from letting another persons problem become your own.***

5. Contract with each other to allow mistakes and to not beat each other up when mistakes are made...learning and taking into account the "Rules of Crisis" (next Page) can help.

Addendum: Necessity of receiving help almost always produces resentment of helper (because it is a reminder of disability)!!

RULES OF CRISIS

Developed and Adapted from and for Numerous Couples and Families
Mike Martelli, PhD

In a Crisis:

- ◆ **Everyone will be at their worst!**
- ◆ **Our/Their behavior and communication will reflect our/their worst!**
- ◆ **We/They will Hold Others Accountable and Excuse Ourselves/ Themselves!**
- ◆ **When We are Hurting, we fail to appreciate Their Hurt!**
- ◆ **Things will get Better or Worse after a Crisis, but will not stay the same!**

RX:

- ⇒ **Learn and Remember and Apply the Rules.**
 - ☑ **Blame the Situation Only**
 - ☒ **Do Not Blame each Other**
 - ☑ **Try to Understand each other**
 - ☑ **Bolster each other Working Together as Teammates with the common Goal of Reducing the Stress!**

10 Tips for Family Caregivers

From the National Family Caregiver's Association (NCFA): <http://www.nfcacares.org/>

- 1. Choose to take charge of your life, and don't let your loved one's illness or disability always take center stage.**
- 2. Remember to be good to yourself. Love, honor and value yourself. You're doing a very hard job and you deserve some quality time, just for you.**
- 3. Watch out for signs of depression, and don't delay in getting professional help when you need it.**
- 4. When people offer to help, accept the offer and suggest specific things that they can do.**
- 5. Educate yourself about your loved one's condition. Information is empowering.**
- 6. There's a difference between caring and doing. Be open to technologies and ideas that promote your loved one's independence.**
- 7. Trust your instincts. Most of the time they'll lead you in the right direction.**
- 8. Grieve for your losses, and then allow yourself to dream new dreams.**
- 9. Stand up for your rights as a caregiver and a citizen.**
- 10. Seek support from other caregivers. There is great strength in knowing you are not alone.**

A Caregiver's Bill of Rights

Excerpted from "A Caregiver's Bill of Rights," Caregiving: Helping An Aging Loved One, Jo Horne, AARP Books, 1985.

I have the right --

- 1. To take care of myself:** This is not an act of selfishness. It will give me the capability of taking better care of my relative.
- 2. To seek help from others even though my relative may object.** I recognize the limits of my own endurance and strength.
- 3. To take pride in what I am accomplishing and to applaud the courage it has** sometimes taken to meet the needs of my relative.
- 4. To protect my individuality and my right to make a life for myself that will sustain** me in the time when my relative no longer needs my full-time help.

Caregiver Self Advocacy

Adapted by M.F. Martelli, Ph.D.: ©1994; 2000. Page 3 of 10

4 Messages to Live By

From the National Family Caregiver's Association (NFCA): <http://www.nfcacares.org/>

What does it mean to be a happy person when you are a family caregiver? How can you gain a feeling of confidence in your abilities and have a sense of pride in your achievements? How do you stand up for yourself, take care of yourself and find a balance between your own needs and those of your loved ones? These are heady questions, and ones that we have discussed often at NFCA.

We've looked for answers in our own experiences, in books, from professionals, and from other caregivers. We've struggled with these issues because they are at the core of our search for meaning and our need to have principles to live by as caregivers. We've now given form to the many ideas we have developed, and we want to share them with you. We call them NFCA's Principles of Caregiver Empowerment. They are the fundamental principles by which we try to live, and we hope you will use them as guideposts in your search for a sense of direction and inner peace.

1. Choose to take charge of your life. Don't let your loved one's illness or disability always take center stage. We fall into caregiving often because of an unexpected event, but somewhere along the line you need to step back and consciously say, "I choose to take on this caregiving role." It goes a long way toward eliminating the feeling of being a victim.
2. Honor, value and love yourself. You're doing a very hard job and you deserve some quality time, just for you. Self care isn't a luxury. It's a necessity. Self care isn't a luxury. It is your right as a human being. Step back and recognize just how extraordinary you are, and remember your own good health is the very best present you can give your loved one.
3. Seek, accept, and at times demand help. Don't be ashamed to ask for help. When people offer assistance, accept it and suggest specific things that they can do. Caregiving, especially at its most intense levels, is definitely more than a one person job. Asking for help is a sign of your strength and an acknowledgment of your abilities and your limitations.
4. Stand up and be counted. Stand up for your rights as a Caregiver and a citizen. Recognize that caregiving comes on top of being a parent, a child, a spouse. Honor your caregiving role and speak up for your well-deserved recognition and rights. Become your own advocate, both within your own immediate caregiving sphere and beyond.

Family Caregiver's Guide

You are not alone

More than 12 million men, women, and children in the United States need some kind of help with daily activities. About five million are working age adults. About half a million are children under age 18.

Where do they get the help they need? Primarily, they are cared for at home by an estimated 18 million family caregivers. A vast majority of caregivers are women. According to one survey, 54% care for their spouses, 21% care for their parents, and 17% care for their children. Over half of them are employed full time.

While most report feelings ranging from anger to guilt to frustration to depression, most all believe that through the caregiving experience they have found inner strength they never knew they had.

You are important

As a family caregiver, there is no one who can do the job you do. Your emotional bond with your loved one makes your relationship special. It cannot be duplicated even though others can provide important services. Your willingness to take on the enormous responsibility of caring for another human being shows an uncommon level of character and compassion. Even though your job is difficult and often seems thankless, you are a role model for everyone who comes in contact with you.

If everyone could make a difference in just one person's life, as you are, the world would be a much better place. As you work to provide care for another, make sure you take time to take care of yourself -- because you are important.

How are you doing?

The biggest mistake a family caregiver makes is usually not involved with patient care -- it involves self care. Family caregivers often don't allow themselves the breaks they need. Sometimes they take the caregiving burden solely on their own shoulders even when there are sources of help. They may wait (resentfully) for others to volunteer to help. When no one does, stress increases and important relationships become strained.

If you've taken on the role of caregiver, pay careful attention to your own well-being: mental, physical, and emotional. When you ask yourself the question, "How am I doing?" and the answer is "Not very well," it's time to get help.

The top 10 needs of family caregivers

1. Information about community resources
2. Help with feelings of resentment and guilt
3. Help with dealing with the patient's feelings of loneliness and depression
4. Information about the patient's diagnosis and prognosis
5. Respite care. A break from caregiving
6. Diet and nutrition information
7. Information about where to get legal advice
8. Help with housekeeping, cooking, and house and lawn maintenance
9. Spiritual comfort
10. The promise that someone else cares about and supports their caregiving work

The 7 signs of caregiver burnout

1. Not eating properly
2. Becoming more emotional
3. Feeling overwhelmed
4. Starting to withdraw
5. Interacting less with peers
6. Having less mental focus at work
7. Having a disheveled unkept appearance

Get information about the basic caregiving functions

Despite the best of intentions, family caregivers can cause harm to their loved ones and to themselves. It is best to get information and, if possible, training in providing basic care. Basic categories include activities of daily living such as --

- Bathing
- Dressing
- Feeding
- Toileting
- Grooming
- Transfers (e.g., bed to wheelchair)
- Moving around

If caregiving involves giving medications, operating or maintaining medical devices, or monitoring physical signs and symptoms, proper training is essential. Caregivers should know CPR.

It is also a good idea to learn about any basic adaptations that would make the home living environment safer or easier to live in.

Other important activities of daily life

In addition to caregiving functions involving the activities of daily living, people needing care (as well as their caregivers) can benefit greatly from various activities such as --

- Conversation and socialization
- Music
- Life recall and life planning
- Physical activity/movement
- Contributions to family, home, and community
- Activities

Some patience and planning in these areas can pay off in a better life for everyone.

Finding the help you need

Take a "tour" of your phone book and Yellow Pages and see what you can find out by talking to:

- Local social service agencies
- Area churches
- Local support groups
- Nursing homes
- Nursing homes that offer short-term stays
- Home health agencies
- Homemaker services
- Chore services
- Adult day care centers
- Companion services
- Personal assistant services
- Respite care services
- Hospice

Some other sources of information

- Families USA Foundation
 - 1334 G Street, NW
 - Washington, DC 20005
- The Center for Applied Gerontology
 - 3003 West Touhy
 - Chicago, IL 60645
 - (312)508-1075
- The National Family Caregivers Association
 - 9621 East Bexhill Dr.
 - Kensington, MD 20895-3104
 - 1-800-896-3650

Check in your bookstore for books such as -- *Helping Yourself Help Others: A Book for Caregivers*

Some Useful Caregiver Internet Links

As Listed on <http://villaMartelli.com>

- **Brain Injury Family Caregiver Site**
<http://www.idrama.com/BrainInjury.htm>
- **Family Caregiver's Help Center**
http://www.ind-homecare.org/pages/help_center.html
- **Caregivers Resources - Midwest Region**
<http://www.mid-eastaaa.org/caregivers.html>
- **Family Caregiver Alliance**
<http://www.caregiver.org/>
- **Family Care America**
<http://www.familycareamerica.com/>
- **Family Care America Newsletter**
<http://www.caregiver.org/newsletter.html>
- **Children of Aging Parents Website**
<http://www.caps4caregivers.org/>
- **Link 2 Care**
<http://www.link2care.net/Link2Care/jsp/default.jsp>
- **National Family Caregiver's Association (NCFA):**
<http://www.nfcacares.org/>
- **Volunteer Locator**
www.casanet.org/program-management/volunteer-manage/
- “Coping With Caregiving”, and Internet Radio Program that has been expanded to include ALL aspects expanded to include ALL aspects of aging, health, family relationships, baby boomer concerns, elder care and senior issues:
www.wsradio.com/copingwithcaregiving
 - **Recent Archives:**
http://12.162.161.64/cart/ProductList.asp?b=8&SearchBy=PR_SubCatID&SearchFor=57.
 - **Older Archives::** www.elderrage.com/ShowArchive.asp.
 - **“Elder Rage, or Take My Father... Please! How to Survive Caring for Aging Parents”:**
www.ElderRage.com

COMPREHENSIVE DOWNLOADABLE CAREGIVER HANDBOOKS

Caregiver Handbook for family and other unpaid caregivers of adults & seniors with disabilities

[www.aasa.dshs.wa.gov/library/ CareGiverhandbook_22-277.pdf](http://www.aasa.dshs.wa.gov/library/CareGiverhandbook_22-277.pdf)

Stroke Caregivers Handbook

www.strokesafe.org/Caregivers_Handbook_rev5.pdf

Advanced Stage Huntington' Caregiver Handbook

<http://endoflifecare.tripod.com/sitebuildercontent/sitebuilderfiles/advancedstagescaregiverhandbook.pdf>

Supplement to Caregivers' Handbook: Family Home Caregivers

http://www.cyf.govt.nz/UploadLib/pdf/fhc_supplement.pdf

Alzheimer' Disease and Related Disorders Handbook REVISED

www.dhr.state.ga.us/Departments/DHR/DHRhandb.pdf

Vision Loss Caregivers Handbook

<http://www.cnib.ca/livingwithvisionloss/>

http://www.cnib.ca/livingwithvisionloss/CNIB_Manual_Text_Eng.pdf

Supporting Caregivers Through Education and Training

<http://www.aoa.gov/carenetwork/Fin-Toseland.pdf>

IDEAS TO HELP YOU FUNCTION EFFECTIVELY

"IDEA" OPTIONS FOR HELPERS

IDEAS TO MAKE YOU DISTURBED

1. It is necessary for me to be loved and approved by my spouse, relatives, and significant others in my life - and if not, it's awful!
 2. I must be thoroughly competent and effective in everything I do, or else it's terrible.
 3. Sometimes my spouse is simply a bad person and undeserving of help, and I should not have to put up with him/her
 4. It is terrible when I am frustrated in my efforts to do a good job, or when obstacles keep things from going the way that I would like.
 5. It is reasonable to become upset if my spouse or family members do not behave in a manner that I think is best.
 6. I should be frustrated if I have to wait for my spouse; or if he/she does not respond immediately to my instructions.
 7. I must get everything done that needs to be done without having to change plans, change my approach, or change my style of working.
 8. If part of my well intended efforts are resisted or if my attempts to help are particularly stressful or threatening, I should worry about it and be preoccupied by it.
1. It's definitely nice to have the approval of my spouse and relatives, but even without it, I can still do my best and be proud of it and accept myself!
 2. Doing things well is satisfying - but, it's human to make mistakes. I forgive myself and will do better next time.
 3. Sometimes people are harder to like and put up with, but I can still try to do a good job and be proud of my efforts with them.
 4. Being frustrated is unpleasant and disappointing, but it is not terrible...it is a normal and natural part of living that I can accept.
 5. Although it would be easier for me if my spouse or others acted the way I want, people will generally act the way THEY want, and I can accept and live with that.
 6. It would be easier if my spouse or family members responded immediately, and worked at my pace, but it is not terrible when they don't, and at least I can control myself by remaining calm and flexible.
 7. It is nice to work without unexpected changes or inconvenience changes, but these things are not terrible...and sometimes there are more things to do than there is time. Making a reasonable effort is what counts.
 8. While it may be difficult not to worry or dwell on stressful events, these are not catastrophic, worrying will not change them, and I've handled stress like this before.

Adapted by M.F. Martelli, Ph.D & J.A. Braith, Ph.D, 1994