



CAREGIVER SURVIVAL RULES

Developed and Adapted by Mike Martelli, PhD: DOI: 10.13140/RG.2.2.22936.32009

1. Caregivers 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 helping, caregiving, treating or being responsible for **Anyone** else or their needs. Ask for help as needed and try to build to one full, then 1.5 full days, etc., and as possible, moving toward a protective caregiving amount of 40 hrs/wk.
2. It is in the patient/caregiver and caregiver's best interest to learn to easily & openly ask others for both emotional and instrumental help! It is imperative that full time caregivers engage in relationships with relatives & friends who give more than they seek for their problems and needs, in terms of:
 - (a) emotional support (i.e., patient listening, without impatience, interjections or efforts at quick fixes, which circumvents the most powerful therapeutic healing, being understood (cf "Men are from Mars & Women are from Venus") - see appendix (p13) for elaboration.
 - (b) instrumental (practical help that is requested) - *For the sake of the caregiver & caregiver.*
 - > Also, ensure that in other parts of life, and in other relationships, most of the focus is on non-caretaking activities, not helping, listening to or attending to needs of others.
3. At least some of the caregiver-caregiver interaction must include non-caretaking activities - i.e. interaction in the patient's areas of residual strengths and competencies - especially for leisure activities. ---> *RX: Perform an inventory of previously or possibly enjoyable activity & start planning & experimenting - non-caretaking activities strengthen the relationship & caregiver health.*
4. Be a "Mirror" and not a "Sponge".
 - Sponging is absorbing another person's negative emotions or anger and reacting to them with similar negative emotions. It is catching the other person's negative emotions and allowing them to control your emotions and reactions.
 - Mirroring is the process of simple, matter-of-fact reflecting back another person's negative emotions (e.g., "You are angry that I did not come when you first called...Hm"), Without (a) emotional reaction, (b) obligation to respond emotionally, or (c) obligation to agree or disagree, and, importantly, (d) without "catching" the emotion & making their problem your own. By its nature, mirroring involves a slow, deliberate and open look at the other person's statements, and prevents escalation of emotions, allowing you to control your emotions by not reacting. It allows under-reacting & keeping a cool head to help calm the situation. Besides not letting another person's problem become your own, it helps defuse their emotions so that they can better hear their message with calmer emotions and more objectively.
5. Understand that resentment of caregivers by caregiver is a too often inevitable emotional reflex because the necessity of receiving help often forces painfully devastating confrontation with deficits, disability & losses in independence & autonomy (by which most persons define themselves) - it forces the confrontation with and reminds of the awfully unwanted need for help. This is especially true for persons accustomed to being in charge and being the caregiver and not the caregiver. Understanding, practice of under-reacting, and ventilation can help.
6. Contract with each other to allow mistakes & not beat each other up when mistakes are made or problems occur. Learn & take into account the "Rules of Crisis" (Page 2).





RULES OF CRISIS

Developed and Adapted from and for Numerous Couples & 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!**

4 Tips for Family Caregivers

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

- **Remember to be good to yourself. Love, honor and value yourself. You're doing a very hard and too often thankless job and you deserve some quality time, just for you.**
- **Watch out for signs of depression, and don't delay in getting professional help when you need it.**
- **When people offer to help, accept the offer and suggest specific things that they can do.**
- **Seek support from other caregivers. There is great strength in knowing you are not alone.**



A Caregiver's Bill of Rights

I have the right – (short version)

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.

I have the right – (long version)

- To seek help from others even though my relative may object. I recognize the limits of my own endurance and strength.
- To maintain facets of my own life that do not include the person I care for, just as I would if he or she were healthy. I know that I do everything that I reasonably can for this person, and I have the right to do some things for myself.
- To get angry, be depressed, and express other difficult feelings occasionally.
- To reject any attempt by my relative (either conscious or unconscious) to manipulate me through guilt, anger, or depression.
- To receive consideration, affection, forgiveness, and acceptance for what I do for my loved one for as long as I offer these qualities in return.
- To take pride in what I am accomplishing and to applaud the courage it has sometimes taken to meet the needs of my relative.
- 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.
- To expect and demand that as new strides are made in finding resources to aid physically and mentally impaired older persons in our country, similar strides will be made toward aiding and supporting caregivers.
- To _____
(Add your own statement of rights to this list.)

--> Read the list to yourself every day.

— Jo Horne, author of *Caregiving: Helping an Aging Loved One* (from: Caregiver.org)



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

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.



10 Tips for Family Caregivers

1. Choose to take charge of your life; don't let your loved one's disability always take center stage.
2. Remember to be good to yourself. Love, honor and value yourself. You're doing a very hard & often thankless 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.

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

Finding the LOCAL help you need (*non-internet resources*)

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

- Local social service agencies and churches and caregiver support groups
- Nursing homes, especially Nursing and Assisted Care Facilities homes that offer short-term stays
- Home health agencies
- Homemaker services and Chore services
- Adult day care centers and Companion services
- Personal assistant services, Respite care services and Hospice

Also consider these sources that usually provide info re: local support –

- Families USA Foundation, 1334 G Street, NW, Washington, DC 20005
- The Center for Applied Gerontology, Chicago, IL 60645, (312)508-1075
- The National Family Caregivers Association, Kensington, MD, 1-800-896-3650
- Check in your bookstore. For example: Helping Yourself Help Others: A Book for Caregivers



Some Useful Caregiver Internet Links & Downloads

(As Listed on <http://villaMartelli.com> under "Caregivers Survival Rules")

- **"Coping With Caregiving" Internet Radio Program**, including ALL aspects expanded to include ALL aspects of aging, health, family relationships, baby boomer concerns, elder care and senior issues: <http://www.programsforelderly.com/caregiver-coping-with-caregiving-radio-program.php>
- **Dr Mike Martelli interview by Caregiver Author Jaqueline Marcell:**
<http://villamartelli.com/Caregiver%20Interview%20MFM.mp3>
- **"Elder Rage, or Take My Father... Please! How to Survive Caring for Aging Parents":**
www.ElderRage.com and Older Archives: www.elderrage.com/ShowArchive.asp
- **Online Caregiver Handbook**
https://www.edumed.org/resources/caregivers-online-handbook/?fbclid=IwAR0eJQqoy_zyFte_gJYWaMsKRUMAEX7IUuM3pPtFTuRIL4rgdYSIOVlv2Y8

Caregiver & Family Handbooks: Online and Downloadable

(Adapted From Martelli, MF and Zasler, ND, 2021)

Name	Resource	Website
Aphasia Caregiver Guide, National Aphasia Foundation	A guide for caregiving to someone with aphasia that covers every type of aphasia and aspect of caregiving, from hospital to home, including taking care of self along with loved one	www.aphasia.org/aphasia-resources/aphasia-caregiver-guide/?gclid=CjwKCAiA1rPyBRAREiwA1Uly8Kx0EYQz-O0gKdEw8hwMgHz0ynN7asCTn3KOMmQ8ml6JuMrkEutZTBoC2KcQAvD_BwE
Barrow Neurological Institute Brain Tumor Handbook	Information, resource, tips & tools to help with understanding brain tumors, symptoms, treatment, treatment process, recovery	www.barrowneuro.org/get-to-know-barrow/centers-programs/brain-tumor-program/brain-tumor-handbook/
Caregivers Companion: A Guide for Caregivers of Service Members and Veterans with TBI	Information and forms that help the caregiving journey (e.g., health care team contact info, medication log, caregiver support worksheet, communication, self-assessment, schedule, home safety checklist, legal documents, insurance, VA health system, continuum of care, sleeves for business cards CD, medical scans tests, etc.; additional downloadable forms. Designed for use as a carry along binder to keep track of important information & keep organized	https://tbi.cemmlibrary.org/getmedia/b2446622-7944-44d2-8137-f97443a93635/Caregivers-Companion-2010 https://tbi.cemmlibrary.org/Resources/For-Caregivers/Caregiver-Guides-Printable https://tbi.cemmlibrary.org/Resources/For-Caregivers/Downloads
Caregivers Guide to Stroke	Booklet with practical tips & resources to help caregivers navigate the often difficult & confusing stroke recovery process, including managing effects, health team communication, legal resources, financial support, health coverage; local support group finder	www.stroke.org/-/media/stroke-files/caregiver-support/caregiver/cargivers-guide-to-stroke-ucm_489454.pdf?la=en&hash=D50D0B352B808697B631CC3391D93A11E939C6BE



<u>DVBIC TBI Guide for Caregivers of Service Members and Vets</u>	Newly updated, a truly comprehensive source of information & support for caregivers (military & civilian) of persons with moderate to severe TBI. Four downloadable modules (approx. 300 pages) that cover Introduction to TBI, Understanding the effects & what to do to help, becoming a family caregiver, & navigating services and benefits. Part of the family caregiver curriculum, an excellent resource for military, veteran and also nonmilitary caregivers	https://dvbic.dcoe.mil/sites/default/files/DVBIC_Manual_Mod_1_2010_updated.pdf https://dvbic.dcoe.mil/sites/default/files/DVBIC_Manual_Mod_2_2010_updated.pdf https://dvbic.dcoe.mil/sites/default/files/DVBIC_Manual_Mod_3_2010_updated.pdf https://dvbic.dcoe.mil/sites/default/files/DVBIC_Manual_Mod_4_2010_updated.pdf https://dvbic.dcoe.mil/family-caregiver-curriculum
<u>EDUMED Caregivers Handbook</u>	<i>Nice online guide with good collection of tools, resources, apps & more, including in-depth solutions to some of caregiving's toughest challenges</i>	www.edumed.org/resources/caregivers-online-handbook/
EDUMED Compassion Fatigue Online Guide	Designed for professional caregivers, but relevant for family caregivers too, this provides information, guides for recognizing & coping with compassion fatigue (or caregiver burnout) that frequently accompanies caregiving	www.edumed.org/resources/compassion-fatigue-online-guide/
<u>Family Caregiver Fact & Tip Sheets, Guides</u>	Taking Care of YOU: Self-Care for Family Caregivers, Coping with Behavior Problems After Head Injury, FCA CareJourney for quality information, support, and resources for family caregivers.	https://www.caregiver.org/www.caregiver.org/fact-sheets https://www.caregiver.org/taking-care-you-self-care-family-caregivers https://www.caregiver.org/coping-behavior-problems-after-head-injury https://fcacarejourney.caregiver.org/
Huntington's Advanced Stage Caregiver Handbook	Information regarding HD, recognizing symptoms, preparing for its progression with general care principles & tips found helpful by other caregivers.	www.huntingtonsnsw.org.au/sites/default/files/Care%20Giver%20Handbook.pdf
**The Living with Brain Injury Series – Downloads (Headway (IE))	An impressive series of comprehensive quality downloadable practical guidebooks & guides, with tips & tools for some of the most important problems associated with brain injury, from brain information to hospital discharge, specific types of cognitive problems, communication, emotional symptoms, alcohol, returning to driving, work, other activities & more. For patients & caregivers/family. Includes planners & checklists and guidebooks for living with brain injury for family, teen's and kid's	https://headway.ie/about-brain-injury/info-resources/ https://headway.ie/wp-content/uploads/2016/11/The-Family-Guide-to-Brain-Injury-1.pdf
Respite Care Notebook	Guides & assists mothers & caregivers of a child with a neurologic disorder to support respite to balance necessary self-care with Practical notebook procedure with tips & tools to guide & assist mothers & caregivers of a child with a neurologic disorder to support taking necessary respite to optimize balanced caregiving	www.childneurologyfoundation.org/wp-content/uploads/2017/09/CNF_Respite_Care_notebook_v5_WEB_int_formv1.pdf
Today's Caregiver Magazine	News and stories for caregivers, including male caregivers	www.caregiver.com/topics/today-s-caregiver-magazine/
Understanding Pediatric Brain Injury: A Guide for Parents and Teachers	Downloadable eBook that helps family, caregivers and teachers understand common thinking, behavioral, emotional and communication changes and outlines strategies to help a child adapt to these changes and issues that may arise when the child returns home, to school & community.	www.mayo.edu/research/documents/updi-parents-teacherspdf/DOC-10027795



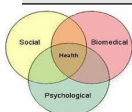
V.A. Family Caregivers Guide to TBI	Brief, basic TBI information with useful caregiving tips	www.caregiver.va.gov/pdfs/FamilyCaregiversGuideToTBI.pdf
VM Holistic Habit & Self Rehab Protocols: CaregiverPackage	Caregiver guides to promote resilience: survival rules, rules of crisis, self-care & assertion, tips (written, radio link), apps, assertiveness	www.villamartelli.com/CaregiverPackage.pdf

Internet Resources for Caregivers & Family *(From Martelli & Zasler, 2021)*

Name	Resource	Website
AARP Family Caregiving	Education, online seminars, educational & medical & financial & local & community resources; connect with other caregivers	www.aarp.org/caregiving/?intcmp=GLBNAV-PL-CAR
Blue Star Families	Support and resources for military families of active-duty service members	www.bluestarfam.org
CareGiving.com	Caregiver network, webinars, general caregiver education; emphasis on taking care of the caregiver	www.caregiving.com
Caregiver Action Network	Forums, peer networks, tool box, resources, tips, videos, support and advocacy for family caregivers, including Caregiver HelpDesk	www.caregiveraction.org
Caregiver's Journey	Traumatic brain injury guide for caregivers of service members and veterans	www.traumaticbraininjuryatoz.org
Caring Bridge	Free service that helps build bridges of care, support & communication between family and friends about their condition and health	www.caringbridge.org
Child Neurology Foundation	Expanding network of patients, caregivers, researchers, volunteers and advocates providing programs for direct specialist peer support & resource assistance in navigating the journey of diagnosis, management& caregiving for of a child with a neurologic disorder, through to transition to adult care	https://www.childneurologyfoundation.org/
Department of Defense Warrior Care	Resources and information for military caregivers	warriorcare.dodlive.mil/caregiver-resources
Easter Seals Caregiver Training Program	Caregiver training classes & wide range of caregiver guides & resources	www.easterseals.com/explore-resources/for-caregivers/ www.easterseals.com/explore-resources/for-caregivers/military-veteran-caregivers.html



Elizabeth Dole Foundation — Caring for Military Families	Caregivers advocacy program	www.elizabethdolefoundation.org
Empowering Caregivers	Newsletters, articles, message boards, resources, exercises	www.care-givers.com
Family Voices (888-835-5669)	Information, support, resources regarding health & advocacy for children with special health care needs	http://www.familyvoices.org/
Family Caregiver Alliance Resource Center, National Center on Caregiving	Caregiver information, education, support, resources, services, links, fact sheets, tips, research & advocacy for caregivers of adults with chronic physical or cognitive conditions like TBI. Best Practice Caregiving, online support groups, phone conferences, learning center, videos, state by state help navigator, caregiving journey sharing; some information in Spanish	www.caregiver.org www.caregiver.org/traumatic-brain-injury www.caregiver.org/carejourney www.caregiver.org/family-care-navigator
Family Caregiver's Help Center	Information re: finding and interviewing a home caregiver, coping with hospice care, guide for family caregivers and independent living	www.indh.urs2009.net/
Family Support Empowerment Program, Child Neurology Foundation	Education, support & programs for direct specialist peer support & guides, resource assistance in caregiving for a child with a neurologic disorder from diagnosis to management & caregiving through to transition to adult	https://www.childneurologyfoundation.org/fsep/
Healthy Caregiver	Community-based outreach, education, and research	www.healthycaregiver.com
Hidden Heroes	Community resources, online caregiver courses, peer support for caregivers of military members	www.hiddenheroes.org
Military Family Caregiving Online Training	Online training for caregiving skills, tips, and resources	www.extension.org/militaryfamilies
Military One Source: Caregivers	Information about available services and benefits for families of service members; resources for caregivers to assist in caregiving for those with severe injury or debilitating illness, including coping with the range of associated emotions, including grief and anger. 24/7 Phone Helpline (800-342-9647) & online chat or video. Caregiver Blog Brigade, Military Families Learning Network, Peer support and forums, financial and health/wellness counseling, downloads, helpful booklets, CDs, DVDs and articles that shipped for free	www.militaryonesource.mil/health-wellness/caregivers
Military and Veteran Caregiver Network	Online forum community, peer support group, peer mentor program structure, local services resource library	www.milvetcaregivernetwork.org



National Alliance for Caregiving	Education, advocacy, research, resources	www.caregiving.org
National Caregivers Library	Extensive resource libraries covering most areas and disabilities, with hundreds of forms, checklists, articles, links, ranging from caregiver basics to self-care and emotional issues, real estate, caregiver employers, government resources and more	www.caregivers.library.org
National Family Caregivers Support Program	State grants to support caregivers	www.aoa.acl.gov
National Military Family Association	Assistance in navigating DoD and VA programs and benefits	www.militaryfamily.org
Net of Care	Information and resources for caregivers	www.netofcare.org
Network of Care	Community resources and tools for caregivers	www.networkofcare.org
Op. Family Caregiver Operation Family Caregiver	Support for caregivers of post-9/11 service members	www.rosalynncarter.org/returning_soldiers
Operation Homefront	Online support for caregivers; financial relief	www.operationhomefront.net
Rosalynn Carter Institute for Caregiving	Caregiver training, mentor programs, advocacy, education, research	www.rosalynncarter.org
Today's Caregiver	News & stories for caregivers (including males), caregiver magazine, articles, newsletter, tips, conference & local resources	www.caregiver.com/
United Service Organization (USO)	Caregiver seminars	www.uso.org
VA Caregiver Support Program	Comprehensive Assistance for Family Caregivers, including general support services, connecting with others, in-home & support services, tips, tools, apps, resources, courses, publications.	www.caregiver.va.gov/
Veteran Caregiver	Peer-to-peer support for caregivers and veterans	www.veterancaregiver.com
Well Spouse Foundation	Support community for peer support, advocacy & education for spousal caregivers	www.wellspouse.org
Working with people with traumatic brain injury (Aus)	Resources & tools to train staff working with TBI; self-study, & workplace learning modules, tool kits, more	www.tbistafftraining.info/index.html
Wounded Veteran Family Care	Support, problem solving & resources to help meet needs of wounded, ill, or injured veterans and families	www.woundedveteranfamilycare.org





Holistic Habit & Self Rehab Protocol: Apps to Help Caregivers

The growing marketplace for apps related to medical and health care includes calendars, medication lists, e-bills, notes, and other info or files to keep critical information. The best part of the apps is having everything all in one place, at your fingertips. On the other hand, using the apps appropriately is very dependent on your technological acumen, as well



1. [Caregiver Buddy](#): If you're caring for a loved one with memory loss, this is the app for you. It provides in-the-moment tricks and ideas to help your loved one cope, as well as live help if things get too difficult to handle on your own.



2. [Caring Bridge](#): This app forms a "bridge" between different members of the caregiving team, and even the loved one themselves, to help coordinate required tasks to ensure the best care. There's even a guest book where you can share information with far-flung friends & family.



3. [CareZone](#): This app offers three distinct helping areas: A journal that allows you to share information on your loved one; a calendar that comes in handy for every situation; a contact section that helps you keep doctors, insurance co's & much more all in one place.



4. [Caring Village](#): This app designed for caregivers offers everything from checklists to assignable to-do lists to a wellness journal that allows you to "check in" with a loved one at any time. Not just for in-home care, this app can be used by those in senior housing or assisted living as well.



5. [Dementia Caregiver Solutions](#): This app offers hope for caregivers with helpful tips on 25 of the most common issues faced by those with dementia. These tips are designed to keep you grounded and hopeful when the going gets tough.



6. [eCare21](#): This virtual care platform touts remote monitoring as a way to help lessen the burden on the healthcare system, insurance companies, and of course, the caregivers themselves. This monitoring can take the form of watching almost everything, from how many hours of sleep a patient gets to what their vitals are at any given time.



7. [Medisafe](#): This reminder app for medications is not only great for the caregiver, but might be excellent for the patient themselves, as it could be one piece of the puzzle that allows them to live independently for longer.



8. [MyMeds](#): This app can pull in many people on a caregiving team, including doctors, patients, caregivers, and even insurance companies or representatives for payment of the medications needed by your loved one. The app works in real time, thus reducing the harm that can come from a mistaken or missed dose.



9. [Pacifica](#): Caregivers who deal with negative thoughts now have an app to combat them. Pacifica provides psychologist-designed tools to break the cycle, including meditation, mood tracking, relaxation and much more.



10. [PainScale](#): Designed for those who suffer from chronic pain, this app diary serves as a way to track pain levels, takes notes on what might be causing that pain, and find tips and insights that can help your loved one become more comfortable.

From: https://www.edumed.org/resources/caregivers-online-handbook/?fbclid=IwAR0eJQgoy_zyFte_gJYWaMsKRUMAEX7IUuM3pPtFTuRIL4rgdYSIOVlv2Y8





"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.

IDEAS TO HELP YOU FUNCTION EFFECTIVELY!

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 MFMartelli & JABraith, 1994, 2004



APPENDIX (in process)

RELATIONSHIP RULES: *For Use with Families, Friends & Lovers by Persons with Disabilities*

- **Be Pleasant to Be around most of the time:** Smile, Compliment, joke, laugh, make them laugh, be **KIND**, appreciate them, etc.
- **Want (not Wish*) and Make effort to get better in weaker areas.** Believe you will improve, be proud of your efforts and show others you have a Plan to Improve, with Pride and Hope.
- **Never Quit making even small steps of progress** so that you, spouse or lover, family, friends, believe and have Hope that things will keep getting better for the future...

* Want = Want it more than Wish It & Work to Make it Happen.



**Or, Golden Rule:
Just Be Kind, Always!**



STAGES OF COMPASSION DEATH:

- **1. Sympathy and Unconditional Acceptance and Help and Understanding (*Compassion*)**
- **2. Anger and Resentment about Spouse/Lover/Friend not being Pleasant or Stressing them, Demanding, Angry, Not Trying Hard to Get Better (*Compassion Fatigue*).** They never stay here. If they aren't coaxed back to #1, they go to #3.
- **3. Numbness.** They lose hope and then compassion (*Compassion Death*). Constantly being stressed, responding to Anger and Getting Angry Turn to Dead Feelings. They Get Numb. They simply are unable to get mad or sad or care about You. They disengage and Leave Emotionally and usually Physically (Divorce, institutionalization, etc.). You are emotionally dead to them.

Antidote: (1) RULES FOR RELATIONSHIPS; (2) CAREGIVER SURVIVAL RULES

MF Martelli, PhD; 1996-2021

Elaborations on Caregiver Survival Rules: Rule #2 (of 6):

1. It's in everyone's best interest to share the Caregivers Survival Rules
2. Caregiver Rule #2. Most relationships should result in the Caregiver getting, overall, more understanding, empathy, support & instrumental help than the non care-giver. The likelihood of Caregiver Burnout and/or Compassion Fatigue and/or serious mental illness in the Caregiver, and decline in the Caregiver, increases greatly with each relationship in which the Caregiver gives more than is received.
3. Non Full-time (FT) Caregivers can't really understand Full-time Caregivers. Part-time care giving (esp if less than several hours daily) is really case management, social work or counseling work. This experience does not provide good understanding of FT caregiving - just ask the author!
4. Caregivers are too often habitual caretakers prone to helping others. It is in the best interest of full time caregivers to have interactions with relatives & friends who, on average, give more instrumental help, support and understanding than they take. It is in the best interest of full time caregivers, after providing others with the Caregivers Survival Rules and asking for help as needed, to avoid interactions with any relative or friend who, on average:
 - a) Doesn't provide patient, non-judgemental and supportive ventilation, with empathy, instead of quickly trying to fix problems & not patiently support & encourage ventilation to fully understand (cf Women from Venus, Men from Mars - don't let them be a Martian). Doesn't read or support Caregiver Survival Rules or give more more emotional help than they ask for for their problems; or
 - b) Doesn't offer or give more instrumental (or emotional) help than they request for their problems.
5. Hearing oneself talk out loud with an empathic, non-judgemental, patient listener who does not become uncomfortable or try to force solutions, is, for many people the most effective type of psychotherapy. Many want to help, but effective (versus intended) help must be informed by the recognition that the a stressed caregiver getting to hear oneself talk out loud without interruption or redirection, is, sorely needed.
6. If providing Caregiver Survival Rules, and especially assertive asking, are unsuccessful (e.g., you come away feeling like you had to reduce their distress, anxiety, or guilt, or like they tried to force simple instrumental solutions when just plain patient listening, ventilation and support were needed), then avoid these relationships.

Coming: **Elaborations on Caregiver Survival Rules 1, 3-6**



Biopsychosocial Health Optimization; *Devised & Adapted by Mike F. Martelli, PhD 2004-2021*
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Elaborations on Caregiver Survival Rule #1 (of 6):

1. It's in everyone's best interest to share the Caregivers Survival Rules

Caregiver Rule #1. It is in the caregiver and caregivee's best interest to ensure the caregiver takes time for self care to prevent Burn Out, emotional exhaustion, depression, and physical health declines caused by stress.

...(In process draft...)

For starters, try scheduling one half day per week off for rest and relaxation, in some from of recreation that *does not* involve helping, caregiving, treating or being responsible for **Anyone** else or their needs. Ask for help as needed and try to build to one full, then 1.5 full days, etc., and as possible, moving toward a protective caregiving amount of 40 hrs/wk.

Elaborations on Caregiver Survival Rule #3 (of 6):

Elaborations on Caregiver Survival Rule #4 (of 6):

Elaborations on Caregiver Survival Rule #5 (of 6):

Elaborations on Caregiver Survival Rule #6 (of 6):

