

**The Comfort of Home™ Multiple Sclerosis Edition:
An Illustrated Step-by-Step Guide for Multiple Sclerosis Caregivers
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with the National Multiple Sclerosis Society**

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How to Avoid Caregiver Burnout

Providing emotional support and physical care to someone with MS can be deeply satisfying, but it can be upsetting. Sometimes it is simply more than one person can handle. The strain of balancing a job, a family, more work in the home, and the care of someone with MS may lead you to feel like a martyr or angry and guilty.

One of the biggest mistakes caregivers make is thinking that they can—and should—do everything by themselves. The best way to avoid burnout is to have the practical and emotional support of other people. Sharing concerns with others not only relieves stress, but also can give you a new slant on problems.

Emotional Burdens

You may think you are the only one to face these problems, but you are not alone. Every caregiver faces—

- the need to hide his or her grief
- fear of the future
- worries about money
- having less ability to solve problems

Dependency and Isolation

Fears of dependency and loneliness, or isolation, are common in families of those who are chronically ill. The person with MS can become more and more dependent on the one who is providing care. At the same time, the caregiver needs others for respite and support. Many

caregivers are ashamed about needing help, so they don't ask for it. Those caregivers who are able to develop personal and social support have a greater sense of well-being.

NOTE

Men who are caregivers face special problems. Often they are not used to doing daily chores around the house. They also lose the emotional support of the spouse who is ill and must now be her support. It is especially important for men to seek out a support system.

Knowing When to Seek Help

“Why doesn't anyone ask how I am doing?” It is easy to feel invisible, as if no one can see you. Everyone's attention is on the person with MS, and they don't seem to understand what the caregiver is going through. Many caregivers say that nobody even asks how they're doing. Mental health experts say it's not wise to let feelings of neglect build up. Caregivers need to speak up and tell other people what they need and how they feel.

Support groups, religious or spiritual advisors, or mental health counselors can teach you new and positive ways to express your own need for help.

Seek out professional help when you:

- are using more alcohol than usual to relax
- are using too many prescription medications
- have physical symptoms such as skin rashes, back-aches, or a cold or flu that won't go away
- are unable to think clearly or focus
- feel tired and don't want to do anything
- feel keyed up and on edge





Checklist **Dealing with Physical and Emotional Burdens**

- ✓ *Do not allow the person in your care to take unfair advantage of you by being overly demanding.*
- ✓ *Live one day at a time.*
- ✓ *List priorities, decide what to leave undone, and think of ways to make the work easier.*
- ✓ *When doing a long, boring care task, use the time to relax or listen to music.*
- ✓ *Find time for regular exercise to increase your energy (even if you only stretch in place).*
- ✓ *Focus on getting relaxing sleep rather than more sleep.*
- ✓ *Take several short rests in order to get enough sleep.*
- ✓ *Set aside time for prayer or reflection.*
- ✓ *Practice deep breathing and learn to meditate to empty your mind of all troubles.*
- ✓ *Allow your self-esteem to rise because you have discovered hidden skills and talents.*
- ✓ *Realize your own limitations and accept them.*
- ✓ *Make sure your goals are realistic—you may be unable to do everything you could do before.*
- ✓ *Keep your eating habits balanced—do not fall into a toast-and-tea habit.*

- ✓ *Take time for yourself.*
- ✓ *Treat yourself to a massage.*
- ✓ *Keep up with outside friends and activities.*
- ✓ *Spread the word that you would welcome some help, and allow friends to help with respite care.*
- ✓ *Delegate (assign) jobs to others. Keep a list of tasks you need to have done and assign specific ones when people offer to help.*
- ✓ *Share your concerns with a friend.*
- ✓ *Join a support group, or start one (to share ideas and resources).*
- ✓ *Use respite care when needed.*
- ✓ *Express yourself openly and honestly with people you feel should be doing more to help.*
- ✓ *When you visit your own doctor, be sure to explain your caregiving responsibilities, not just your symptoms.*
- ✓ *Allow yourself to feel your emotions without guilt. They are natural and very human.*
- ✓ *Unload your anger and frustration by writing it down.*
- ✓ *Allow yourself to cry and sob.*
- ✓ *Know that you are providing a very important service to the person in your care.*





- feel sad all the time
- feel intense fear and anxiety
- feel worthless and guilty
- are depressed for two weeks or more
- are having thoughts of suicide
- have become or are thinking about becoming physically violent toward the person you are caring for

When Hostility Builds to the Breaking Point

Anger is a common emotion for caregivers and for the person being cared for. The situation feels—and is—unfair. Both may say hurtful words during a difficult task. Someone may slam a door during a disagreement. Shouting sometimes replaces conversation. Anger and frustration must be addressed and healthy outlets found as a way to let off steam. If they are not, angry situations can become physically or emotionally abusive.

You can control your emotions by letting go of anger and frustration in a safe way.

- Take a walk to cool down.
- Write your thoughts in a journal.
- Go to a private corner and take out your anger on a big pillow.

Where to Find Professional Help or Support Groups

- the community pages of the phone directory
- the local county medical society, which can provide a list of counselors, psychologists, and psychiatrists
- religious service agencies
- community health clinics

- religious and spiritual advisors
- National MS Society
- United Way’s “First Call for Help”
- a hospital’s social service department
- a newspaper calendar listing of support group meetings
- parish nurses

Ask for help from a counselor who is familiar with the needs of caregivers.

Take Care of the Caregiver

Many caregivers neglect their own physical health. They ignore what is ailing them and don’t take steps to avoid getting sick, such as exercising, eating a proper diet, and getting regular medical examinations.

Many caregivers do not get enough sleep at night. If sleep is regularly broken up because the person with MS needs help during the night, talk about the problems with a healthcare professional.

The person with MS needs a healthy caregiver. Both partners need uninterrupted sleep.

How to Let Friends Help You

Outside Activities

Successful caregivers don’t give up their own enjoyable activities. Many organizations have respite care programs to provide a break for caregivers. Other family members are often willing—even pleased—to spend time with the person with MS. It may be possible to have respite care on a regular basis. Keep a list of the people you can ask for help once in a while.





If your friends want to know how they can help ease your burden, ask them to:

- telephone and be a good listener as you may voice strong feelings
- offer words of appreciation for your efforts
- share a meal
- help you find useful information about community resources
- show genuine interest
- stop by or send cards, letters, pictures, or humorous newspaper clippings
- share the workload
- help hire a relief caregiver

It helps to remember the saying, “Grant me the serenity to accept the things I cannot change, the courage to change the things I can, and the wisdom to know the difference.”

RESOURCES▶

Caregiver.com

www.caregiver.com

Maintains one of the most visited caregiver sites on the Internet. Publishes Today’s Caregiver Magazine. Provides links to many resources such as government and non-profit agencies.

Caregiver Survival Resources

www.caregiver911.com

A comprehensive list linking caregiving information and services for general issues and specific chronic illnesses.

Center for Family Caregivers/Tad Publishing Co.
www.caregiving.com or www.familycaregivers.org
Develops and distributes educational materials on caregiving, including a newsletter. Caregiving informational kits are \$5 each; please specify new, seasoned, and transitioning caregiver when requesting a kit.

Lotsa Helping Hands
www.lotsahelpinghands.com
Provides a free-of-charge Web service that allows family, friends, neighbors, and colleagues—the community circle of a person with MS—to assist more easily with daily meals, rides, shopping, baby-sitting, and errands that may become a burden during times of medical crisis.

MSWorld
www.msworld.org
MSWorld offers online bulletin boards and chatrooms for people with MS and their family members. There is a board for partners, family members, and friends.

National Alliance for Caregiving
4720 Montgomery Lane, 5th Floor
Bethesda, MD 20184
www.caregiving.org
The Alliance is a non-profit coalition of national organizations focusing on issues of family caregiving.

National Family Caregivers Association
10400 Connecticut Avenue, Suite 500
Kensington, MD 20895
(800) 896-3650
info@thefamilycaregiver.org
www.thefamilycaregiver.org
Free member benefits include Take Care!, a quarterly newsletter; The Resourceful Caregiver, a useful guide to resources; a support hotline and online chat room.





National Multiple Sclerosis Society

(800) FIGHT-MS (800-344-4867)

www.nationalmssociety.org

Offers a wide variety of programs and services to include self-help groups, for people with MS and their families.

Today's Caregiver Magazine

6365 Taft Street, Suite 3003

Hollywood, FL 33024

(800) 829-2734

www.caregiver.com/magazine

Bimonthly magazine dedicated to caregivers.

Well Spouse Foundation

63 West Main Street, Suite H

Freehold, NJ 07728

(800) 838-0879

info@wellspouse.org

www.wellspouse.org

Publishes Mainstay, a bimonthly newsletter and provides networking/local support groups.

Check with your local church or health facility to see if they sponsor **Share the Care** teams.

Publications

Care for the Family Caregiver: A Place to Start, a report prepared by HIP Health Plan of New York and National Alliance for Caregiving. Available at www.caregiving.org

A Guide for Caregivers published by the National MS Society.

Helping Yourself Help Others: A Book for Caregivers, by Rosalynn Carter, with Susan Golant. Random House/Time Books, 1995.

(800) 733-3000

Plenty of basic information for caregivers.

Love, Honor and Value: A Family Caregiver Speaks Out about the Choices and Challenges of Caregiving, by Suzanne Geffen Mintz

Mainstay: For the Well Spouse of the Chronically Ill by Maggie Strong

Multiple Sclerosis: A Guide for Families by Rosalind C. Kalb, PhD (ed.). Demos Medical Publishing, 2006. 293 pp. \$24.95.

Contains chapters on topics ranging from emotional and cognitive issues, to sexuality and intimacy, to life planning.

Positive Caregiver Attitudes by James Sherman, PhD

If you don't have home access to the Internet, ask your local library to help you locate any Web site.

