Multiple Sclerosis

300 TIPS FOR MAKING LIFE EASIER

Acclaim for the first edition
“Full of wonderful ideas on everything from home safety and accessibility to dressing and grooming... An absolute “must have” for every individual with MS.”
— The MSAA Motivator

This extensively revised second edition of Multiple Sclerosis: 300 Tips for Making Life Easier contains tips, techniques, and shortcuts to help people with MS organize and simplify their lives. From basic principles to specific ideas, this book is packed with helpful information for those coping with the special challenges of a chronic illness. Updated chapters cover Home Safety and Accessibility, Computers and Technology, Grooming and Dressing, Managing Mealtime, and much more.

NEW sections include
• Managing medical issues
• Travel tips for weekend getaways or extended travel
• Unique product suggestions that make everyday tasks easier
• Resource section to easily locate products and services

Learn how to conserve valuable time and energy, develop practical techniques for streamlining everyday routines, and enjoy life to the fullest!

About the Author
Shelley Peterman Schwartz and her husband Dave live in Madison, Wisconsin. At the time of her MS diagnosis in 1979, Shelley was working as a teacher of the deaf. Since 1985, she has published more than 500 articles and received numerous awards including the Mother of the Year from the Wisconsin Chapter of the National MS Society, the Partner in Health award from the Combined Health Appeal of America, and the Spirit of the American Woman Award from JC Penney. Her nationally syndicated column, “Making Life Easier,” appears in numerous newspapers and magazines across the country.

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Multiple Sclerosis 300 Tips for Making Life Easier

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Shelly Peterman Schwarz
This is a sample from Multiple Sclerosis
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Multiple Sclerosis

300 TIPS
for Making Life Easier

Second Edition

Shelley Peterman Schwarz

Published by Demos Health
Dedication

To Judy Ross, my mentor, cheerleader, and dear friend: Thank you for believing in me!

To Ina Sharkansky, my quiet, unwavering supporter: Thank you for your kindness and friendship.

To Deborah Proctor, my right arm and able assistant: Thank you for all your hard work!

To my husband, David: There are no words to adequately thank you for giving me the freedom to live my life to the fullest. YOU are a remarkable man!

To all my wonderful friends and neighbors: Please know that I couldn’t do what I do without you, and you have my deepest, heartfelt thanks.
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As we move forward into the twenty-first century, most people in this country are leading lives that are complex and frenetic. The imposition of a chronic condition such as multiple sclerosis (MS) may tip the delicate balance of daily activities into a situation that rapidly becomes unmanageable. The extra time needed to perform routine tasks not only is inconvenient but also may take the joy out of activities such as travel and recreation. Fatigue, perhaps the most common symptom encountered in MS, is also an impediment to getting things done efficiently.

In this book, Shelley Peterman Schwarz shares with you 300 simple tips that will make your life easier. They grew out of her own experience of living with MS and its related disability, which gives them their “tried and true” flavor. Ideas span all aspects of daily life, from dressing and grooming to medical issues and recreation. The happy result is time and energy saved, and frustration dramatically reduced. Shelley’s tips will often surprise you with their simplicity and amaze you with their helpfulness.

Nancy J. Holland, Ed.D., R.N.
Vice President, Professional Resource Center
National Multiple Sclerosis Society
A Word from the Author

Dear Reader,

It is my pleasure to present this second edition of *Multiple Sclerosis: 300 Tips for Making Life Easier*. It doesn’t seem possible that I have had MS for more than 25 years. I still vividly remember that dreary August day in 1979 when I was diagnosed. I remember what I wore, where I parked the car, how the drizzling rain helped hide the tears welling up in my eyes, and how my husband and I held each other after I told him.

In the beginning, I was relieved that there was a name for my minor but ever-present complaints: numbness and tingling up and down my spine, clumsy fingers, and an inability to run after the children as fast as I used to. Then reality hit and the fear took over. What about the future? How would MS change me and the life my husband and I shared? How would the illness affect our children, Jamie, age 5, and Andy, age 3?

A lot has happened since my diagnosis. The disease has left me with no use of my legs or dominant right arm. My weakened left hand can’t even turn a doorknob or squeeze a tube of toothpaste. But despite all that, I’m happier now than I have ever been before, and I live a remarkably unlimited life.

If you wonder how that is possible, let me try to explain. I think one of the reasons is that I’ve been a lifelong problem-solver. Each time I have faced a problem that MS has imposed, such as dressing myself independently, I have taken it as a personal challenge. I have had to find ways of consolidating, streamlining, and rearranging the way I do simple everyday tasks. I began developing my own tips, techniques, and time-savers and soon realized that everyone has their own ideas for making life easier. I became a keen observer of how
other people do things. Even today I look at obstacles and inabilities as problems waiting for a solution. After years of all sorts of personal and professional challenges, I have discovered that I am quite creative and resourceful. There are not many things I “can’t” do.

About twenty years ago, I began writing down my personal tips and those I observed from other people. My nationally syndicated column, “Making Life Easier,” is the result of years of problem-solving. My tips and ideas have appeared internationally, including Inside MS, Real Living with Multiple Sclerosis and MS Life (Australia).

In this second edition, all the company and association contact information has been verified, and updated, and web site URLs have been added. In addition, there are more than 50 new product recommendations and resources for locating unique goods and services to help you with everyday activities. And the chapter “Personal Empowerment” has been divided into three chapters: “Taking Care of You”, “Managing Medical Issues”, and “Weekend Getaways and Extended Travel” to provide you with more information.

In 2001, my husband and I created Meeting Life’s Challenges, LLC. Our mission is to reach out and support people who are coping with chronic illness/disabilities, their family members, and healthcare professionals by offering practical lifestyle information, helpful strategies, and motivation.

When you live with a chronic illness such as MS, it may be hard to predict good days and bad days, let alone the future. I hope these tips help you increase the number of good days you have and encourage you to develop your own techniques for Making Life Easier. I am convinced that finding ways to adapt, modify, and simplify your life will give you the greatest opportunity to be happy and enjoy each day to the fullest.

Sincerely,

Shelley
P.S. I would love to hear from you and learn how you’re Making Life Easier. Please send your tips or message to me at Shelley Peterman Schwarz, Meeting Life’s Challenges, LLC, 9042 Aspen Grove Lane, Madison, WI 53717

help@MakingLifeEasier.com  help@MeetingLifesChallenges.com
CHAPTER 1

General Tips for Making Life Easier

Being diagnosed with multiple sclerosis (MS) forced me to simplify my life. I was 32 years old, and it was clear that life as I knew it had changed forever. As much as I wanted to deny it, I could not physically, mentally, or emotionally keep up the break-neck pace I demanded of myself.

As I began writing this book, I realized there were several overriding principles that everyone with a chronic medical condition like MS should know:

- Alternate periods of activity with periods of rest
- Plan ahead
- Take advantage of labor-saving devices and new technology

In this chapter, you will learn the most basic lessons for conserving time and energy, so that you will be able to do what you want to do. Using these techniques, you will be more organized, able to work smarter, and, most important, more independent than you otherwise would have been.

At times, I have included unique products that make everyday tasks easier. Some are available in drug stores, discount department stores, building supply stores, and home improvement stores. Others are unique and more difficult to find (i.e., tube pens to make writing easier or offset door hinges for making doorways wider); these are marked with a 🌼. A resource section at the end of each chap-
Multiple Sclerosis: 300 Tips for Making Life Easier

General Tips

1. Keep balance in your life. Prioritize, eliminate, consolidate, and streamline activities in all aspects of your life.
2. Take care of yourself. Be sensible about how you spend your time and energy. Do those things that are most important to you and to your family. Try to eliminate unnecessary or difficult tasks. Give yourself permission to rest; put your feet up whenever possible. Make compromises and remove the word “should” from your vocabulary.
3. Pace your activities; try to break an activity down into a series of smaller tasks. Rest before you become exhausted and, if need be, enlist the help of others.
4. Eat a healthy diet. Do not skip meals. Carry trail mix, nuts, and/or fresh fruit with you. Eat a healthy snack, and avoid the temptation to grab a candy bar with hollow calories and little nutritional value.
5. Arrange your home for your convenience. Sometimes, this means putting furniture in strategic locations to help you walk from room to room or placing a chair halfway down a long hallway so that you can stop to rest. Sometimes, it means purchasing duplicate cleaning supplies for both upstairs and downstairs rooms.
6. When you need help, take advantage of the products, services, and people available. When you need something or someone to help you, don’t look at it as giving in. Instead, look at it as making an intelligent decision that will make your life easier and safer.
7. Use technology. New technology is created every day that may make it easier for you to do what you want to do. Remote-
controlled devices and cordless phones save steps. Speakerphones, answering machines, and wireless intercoms can be used to save time and energy. Computers are good for keeping records, keeping a journal, and writing letters. An electronic personal data assistant (PDA) can be synchronized with your computer and help you keep track of appointments and your schedule. An Internet connection can expand your research capabilities and provide opportunities to communicate with others who have MS. Keep abreast of changes, and make full use of every option helpful to you.

8. Walkie-talkies can help you communicate around the house or while shopping, traveling, at museums, theme parks, art shows, or anywhere you might become separated from others in your group. They also can be used to monitor someone sleeping in another room. Walkie-talkies are sold at electronic, discount, or office supply stores.

9. Use labor-saving devices. Many labor-saving devices are available to make almost any task easier. For example: Reachers come in various lengths, weights, and means of operation; find the styles that work for you in various situations (reaching cans on a shelf, picking something up off the floor, etc.). Automatic can and jar openers, toothpaste twisters, hair dryer holders, and quick-release mop and tool holders are just a few of the many products that may make everyday tasks easier for you to accomplish.

10. When shopping, pushing a grocery cart may give you added stability as you walk. If fatigue is a problem, use a wheelchair or scooter anywhere excessive walking is a probability. A growing number of stores, shopping malls, museums, zoos, art galleries, and attractions provide three-wheeled battery-operated scooters or wheelchairs for patrons who tire easily or have trouble walking. Scooters and wheelchairs usually are available on a first-come, first-served basis at the service desk or information booth.

11. Before going out, call ahead to a restaurant, theater, new doctor’s office, and so forth, and ask if the facility is handicap-
accessible. Ask about parking facilities and where the restrooms are located, the most convenient entrance, and so on—anything that might create a challenge or concern you.

12. When noisy environments in restaurants, grocery stores, and department stores exhaust you, select quieter places in which to spend your time. Look for places with drapes, low ceilings, and carpeted or vinyl floors that absorb the sound; avoid establishments that have wooden floors, loud background music, multiple TVs, or high unfinished ceilings. As an added safeguard, carry earplugs in your purse or pocket.

Community Resources

13. Contact the National Multiple Sclerosis Society (NMSS) to find out about client services and support groups. Their telephone number is 1-800-FIGHT-MS. The NMSS can tell you about current research and treatments that will help you keep a positive attitude and give you hope for the future. Some NMSS chapters have “loan closets.” From which members may borrow devices to make daily living easier.

14. Consider joining an MS or other support group. If you are reluctant to attend because you’re afraid you will see others with more advanced cases and you don’t think you can emotionally handle it, attend an MS group for the newly diagnosed or talk on the phone with people who have MS. Another alternative for getting the support you need is to contact a local hospital or clinic to see if they offer coping-type support groups for people with chronic illness or those who are going through life-altering changes.

15. Contact your local independent living center (ILC). Every community in the United States is part of a national network of more than 500 community-based, nonprofit, independent living centers that serve people of all ages and disabilities and their families. ILC goals are information and referral, advocacy, peer support, and independent living skills.
training. The following are a few examples of their many services:

- Assist you in finding out about disability services in your community
- Connect you with others to advocate for changes in the law or rules
- Help you hire and manage personal care attendants
- Put you in contact with people who have faced challenges similar to your own

Most centers have adaptive gadgets and devices that you may borrow and try for a while at no cost, and a vast computer database of the companies and manufacturers that make these products.

Your local library, hospital, or social services agency should be able to assist you in finding the nearest ILC. For a national directory of Independent Living Centers, contact the National Council on Independent Living, 703-525-3406.

16. Contact a hospital rehabilitation department and speak with an occupational or physical therapist about those assistive products that you feel would be helpful. You also might call local medical supply companies, home health agencies, and/or hospital stores to see if they have devices in stock. Whenever possible, try out a device before purchasing it.

17. Research books at the library and through online sources for information, agencies, and organizations that can help you to meet your personal life challenges.

Life is all about choices, and I’m convinced that, if you follow these basic principles, you’ll feel better, have more control, and get more enjoyment out of your life.
Resources

Organizations and Agencies

ABLEDATA
National Institute on Disability and Rehabilitation Research
U.S. Department of Education
8630 Fenton Street, Suite 930
Silver Spring, MD 20910
800-227-0216
www.abledata.com

National Council on Independent Living
1916 Wilson Boulevard; Suite 209
Arlington, VA 22201
703-525-3406
TTY: 703-525-4153
www.ncil.org

The National Library Service for the Blind and Physically Handicapped
Library of Congress
Washington, DC 20542
202-707-5100
TTY: 202-707-0744
www.loc.gov/nls

The National Multiple Sclerosis Society (NMSS)
733 Third Avenue
New York, NY 10017
800-FIGHT MS (344-4867)
www.nmss.org
Chapter 1 - General Tips for Making Life Easier

Books and Newsletters

The Complete Directory for People with Disabilities
2005 Edition
Grey House Publishing
185 Millerton Road
P.O. Box 860
Millerton, NY 12546
800-562-2139
www.greyhouse.com/disabilities.htm

Disabilities Resources Monthly
Disability Resources, Inc.
Dept. IN
Four Glatter Lane
Centereach, NY 11720-1032
631-585-0290
www.disabilityresources.org

Resources for People with Disabilities and Chronic Conditions

Living with Low Vision: A Resource Guide for People with Sight Loss
Resources for Rehabilitation
22 Bonad Road
Winchester, MA 01890
781-368-9094
www.rfr.org
Making Life Easier and Other MS-Related Books
Demos Medical Publishing, LLC
386 Park Avenue South, Suite 301
New York, NY 10016
800-532-8663
www.demosmedpub.com

Meeting Life’s Challenges, LLC
9042 Aspen Grove Lane
Madison, WI 53717-2700
608-824-0402
www.MeetingLifesChallenges.com

Adaptive Devices and Independent Living Aids
Assistance Dog United Campaign
1221 Sebastopol Road
Santa Rosa, CA 95407
800-284-DOGS (3647)
www.assistancedogunitedcampaign.org

Attainment Company, Inc. (Speech and Language Impairments)
504 Commerce Parkway
P.O. Box 930160
Verona, WI 53593-0160
800-327-4269
www.attainmentcompany.com

Lighthouse International (Low Vision)
The Sol and Lillian Goldman Building
111 East 59th Street
New York, NY 10022-1202
212-821-9200
800-829-0500
www.lighthouse.org
Sammons Preston Rolyan–AbilityOne Corporation
(General and Medical)
P.O. Box 5050
Bolingbrook, IL 60440
800-323-5547
www.sammonspreston.com