BY JULIA GRAHAM

How I cope with progressive MS

he range of symptoms and experiences that are lumped together under the label of multiple sclerosis is as great, I believe, as the number of people who have received the diagnosis. While some people who

get it can declare that it "isn't that bad," treat their condition effectively with drugs, and live on in relative normalcy, others have a much different time of it. At the far end of the spectrum are people like me, who are devastated by losses of ability and function and find that our lives have been inconceivably altered. I wish that knowing we are in the minority made me feel better.

From the time of my first symptom, optic neuritis, until I had to take a disability retirement from my job as a postal carrier was just three-and-a-half years. Previously I had walked eight or nine miles a day; by then I could no longer walk more than a few steps, my vision was poor, and my bladder control nearly

gone. It has become progressively worse in the 12 years since then.

When the first ophthalmologist suggested that my optic neuritis could be the presenting sign of MS, I was determined and positive that it



Julia Graham has unusually severe MS. She is blunt about the limitations it has forced on her. Nevertheless, her response to what has happened to her may be of use to others who are living with this disease, whether their experience is severe, moderate, or mild.

wouldn't get me. One of my sisters had been diagnosed with MS so I knew what it looked like—and I didn't want any part of it. (Now there are three of us in a family of ten siblings who cope with the progressive form of it.) I had always been healthy and kept a good attitude. Surely I could overcome anything. That's what I was thinking, but I was wrong.

I tried a lot of things to make it better: chiropractic therapy, yoga, bee stings, a macrobiotic diet, acupuncture, heavy doses of antibiotics, and, when it became

I slowly shifted my perspective to an attitude of acceptance.

available, the first disease-modifying therapy. Nothing worked. In fact, when I took the interferon therapy I happened to be in the 5% of people who reacted with the side effect of infection. Mine was unusual, a huge systemic infection that resulted in several extended stays in the hospital, multiple surgeries, and two years time to recover.

I hung onto my optimism through it all. But I finally got the picture. I'm a person disabled by a horrid disease that I'll live with until I die. When the anesthesiologist came to talk with me before a surgery I asked him to put a little something in the IV mix so I wouldn't have to wake up. But that didn't happen. I'm still here.

Because of my nature and personality I slowly shifted my perspective to an attitude of acceptance. Today I acknowledge and deal with the negative aspects of my

existence. I have good family, friends, and helpers who feed me, get me into and out of bed with a mechanical lift, and much more.

Voice-recognition software on my computer gives me the ability to communicate by e-mail and letters. With a high-speed Internet connection I can view live Webcams in places from the Trinidad Pier in northern California to Times Square in New York City. I play Scrabble with people or on the computer, and enjoy the beauty of flowers and birds in my backyard.

For many years I've solved cryptograms for fun. Now I am creating some of my own and have a Web site to share them with others at www.jgpuzzles.com.

I liked myself as I was before all this happened and I miss being that person. My life is nothing like what I would have chosen or hoped for myself and I think I have plenty of justifiable reasons to complain. I try to allow myself to complain without guilt. There are some moments when I feel enough contentment that I verge on happiness, and, every day, I do the best I can.

Julia plays Scrabble on her porch in the year-round moderate climate of Northern California.

InsideMS invites you to comment on this story. Have your feelings about MS been similar to Julia's in any way? Or completely different? You may reply by e-mail (editor@nmss.org) or paper mail (InsideMS, 733 Third Avenue, 3rd floor, New York, NY 10017).

An afterword to Julia's story

BY KAYE HOOPER, RN, RM, MPH, MSCN, NURSE CONSULTANT USA/AUSTRALIA

haven't met Julia or spoken directly with her, but in my many years of MS nursing, I have met other "Julias."

She tells of her personal experience of living with severe MS—the disappointments and the achievements. Julia zeros

in on some important issues in her story, ones I would like to highlight for everyone who is facing MS.

One of the first challenges Julia discusses is the matter of being diagnosed with MS that turns out to be a very severe type. Julia is in the minority. As she points out, this is a stark reality for her.

The majority of people diagnosed with MS do not have severe MS. Indeed, the majority of people with MS do not have other family members who have MS. But even though most people diagnosed with MS will not encounter the severe course Julia has experienced, each person faces personal grief and sadness, has very real losses, and has to work for redirection after being

diagnosed. These are universals, even though, as Julia reminds us, not everyone with MS has the same story!

Management and treatment of MS are important regardless of the level of

severity. I have always told my patients to get information. There is plenty of help out there. MS health professionals have knowledge and skills to share. Other people who live with MS may understand exactly what you're going through. Don't feel that once diagnosed you're all alone. You can

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R₁
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make a start finding help that works for you by asking your health-care professional and by calling your National MS Society chapter. The toll-free number (1-800-FIGHT-MS) automatically connects callers to the nearest Society office.

Today, there are choices among therapies to control MS. None are perfect but they really do work to delay the

onset of disabilities for many people. In addition, there are treatments and management tools that reduce symptoms and help maintain quality of life for almost everyone.

Julia's support network is a great example for everyone. Julia acknowledges the importance of family, friends, and caregivers around her. These people are her support in her daily life. Everyone with MS needs a network! Having a network of specialists means you can access MS information from many sources in order to make the best choices. Importantly, because MS affects not only you, the person with MS, but your family members and friends, there is help for them too. There are self-help groups, counselors, Web casts, publications, and educational programs focused on what you, your family members, employers, or caregivers need.

Make your environment user-friendly and safe. Dwellings, vehicles, and work spaces can be modified to accommodate MS needs. There are specialist health professionals (occupational therapists, for example) who can advise on how to make an environment safer and easier to get around. Major improvements may come from minor changes like installing hand rails or changing how you use available rooms. Financial aid or volunteer help may be available for planning and construction of larger-scale home modifications, such as creating an accessible bathroom or kitchen. Making changes to the home can remove some of the restrictions caused by disability, increasing personal freedom.

Julia sees herself as "optimistic and having a positive attitude" despite her significant losses. This has helped her persevere and see beyond her MS. Julia is a great deal more than MS. She's developed new interests, channeled her skills, and learned to use the Internet for Scrabble games and the cryptograms she creates.

We have to acknowledge that some days it's hard to see anything but the negative. Feeling sad or blue happens to most people, and it's part of being diagnosed with MS. But continuing to feel blue or negative day after day is not normal. It may be a sign of clinical depression. There is an increased incidence of depression in people with MS, which is not necessarily connected to how disabled a person is. Getting diagnosis and treatment for depression is very important.

Julia's story is her unique story. She's traveling a difficult road and she has stubbornly persevered. When she says quietly that she does the best she can, I hear her telling us that part of how she copes with MS is taking time to smell the roses.

Kaye Hooper is the author of the National MS Society booklet "Managing Progressive MS", which outlines symptom management



and coping strategies when progressive MS makes the road rougher. Ask your chapter for a copy, or visit nationalms society.org/Brochures-ManagingProg1.asp to read it online.

Armies of information for people with progressive MS

sk your chapter about the Society's free pamphlets and fact sheets first. We also suggest that you search the Society's Web site using keywords "progressive MS". You'll find more than 600 references, including archived Web casts and research reports.

Finally, we've listed here some of the most highly praised books, but there are many others, including a rainbow of first person accounts. These books may be in your chapter's lending library. Prices from Demos cite a special discount when you order from their Web site.

Meeting the Challenge of Progressive
Multiple Sclerosis by Dr. Patricia
K. Coyle and June Halper, MSN,
ANP, FAAN. 136 pp. Demos, 2001,
\$21.95.

"Starting with Chapter 4, 'Managing the Symptoms,' the language is understandable, intelligent, friendly, enlightened, and enlightening. All aspects of health issues are addressed—even sex, housing, adaptive equipment, filing for benefits, insurance, and taxes!

This book is a 'must have' for every person with primary- and secondary-progressive MS."

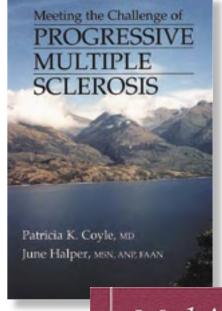
—Dale K. Goodman, for **InsideMS**.

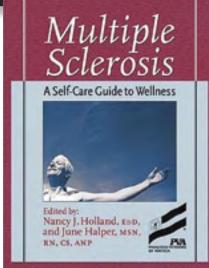
Multiple Sclerosis: A Self-Care Guide to Wellness, 2nd edition edited by Nancy J. Holland, EdD, and June Halper, MSN, RN, CS, ANP. 288 pp. Demos, 2005. \$19.95.

"Written with detail and consideration for someone who has MS. ... It explains medicines, gives the bad and good ... the resources ... and practical information with respect. It has great

insight into all foreseeable problems of someone with MS. Although it takes care to explain mainstream medicine, it doesn't reject a person's right to try alternatives. I don't know the authors, but they did a great job.

Since I was diag-





nosed with MS years ago, I read every book on MS. This book is going right on my kitchen shelf ..."

—M. Wit, on **Amazon.com**.

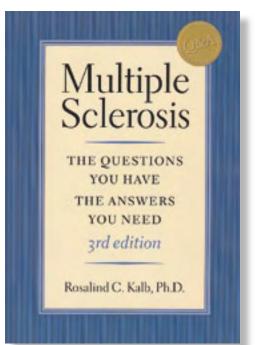
Multiple Sclerosis: The Questions You Have; The Answers You Need, 3rd edition edited by Rosalind Kalb, PhD. 659 pp. Demos, 2005. \$33.98.

"A solid reference work that should be available to anyone with MS, carers, and others working in the field. ... Each of the 17 chapters, written by an expert in MS, addresses a specific topic.

There is much to recommend for those seeking substantial knowledge of MS in one book."

—Tom Houle, Persons with MS International Committee, for MS in Focus.

The Comfort of Home, an Illustrated Step-by-Step Guide for Caregivers, 2nd edition, by Maria M. Meyer with Paula Derr, RN. 384 pp. Care Trust Publications, available through Demos, 2002. \$23.



"This user-friendly manual will help caregivers deal with home care from financial and health-care decisions to day-to-day basics. There is practical information on medical emergencies, home adaptations, avoiding burnout, travel and leisure activities, and long-term planning. ... Clear illustrations show appropriate equipment and techniques for moving or transferring a person with disabilities.

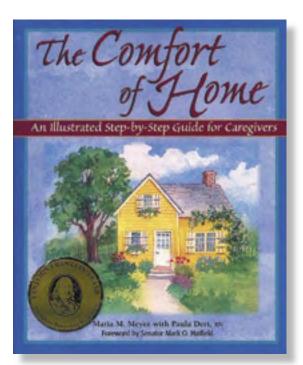
This book should lighten the load for anyone giving or receiving care at home."

—Theodosia T. Kelsey, OTR, FAOTA, a home-care specialist, for **InsideMS**. [An MS-specific edition of this book should be available later this year.]

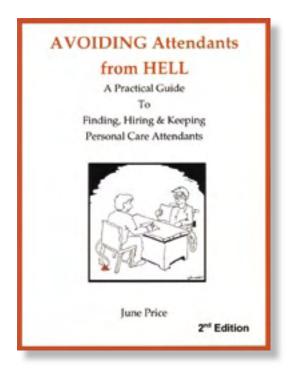
Avoiding Attendants from Hell: A Practical Guide to Finding, Hiring, & Keeping

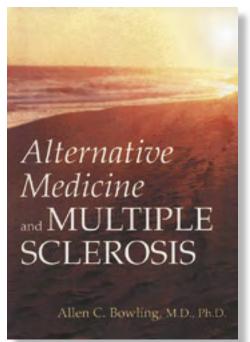
Personal Care Attendants, 2nd Edition, by June Price, with illustrations by Barry Whitesell. 120 pp. Science & Humanities Press, 2002. \$16.95.

"The author writes from twenty years of personal experience hiring, managing, and when needed, firing personal-care attendants ... The book is spiral-bound and well organized. While it is not presented in large print,



60





pay for it through funding or budgeting. This book is for you especially if you don't currently use computers or other assistive technology.

I loved this book for demystifying assistive technology. It makes accessible computers ... accessible!

—Jane Gershaw, retired clinical psychologist, for **InsideMS**.

the layout is very easy to read and chapters have wonderfully descriptive titles. Includes sample want ads, employment applications, live-in contracts, and other useful documents.

I recommend this book to anyone who is considering hiring an attendant."

—Deborah Miller, PhD, LISW, for **InsideMS**.

Computer & Web Resources for People with Disabilities: A Guide to Exploring Today's Assistive Technology by the Alliance for Technology Access. 386 pp. Hunter House Publishers, 2004. \$31.95.

"This book shows you how to find or adapt a computer that will work for you—whatever your disability—and how to

Alternative Medicine and Multiple Sclerosis by Allen C. Bowling, MD, PhD. 272 pp., Demos, 2001. \$24.95.

"Rarely does a publication address an unmet need as thoroughly as (this one does). Dr. Allen Bowling is uniquely qualified, having both a doctorate in pharmacology and clinical experience as a

> neurologist treating people with MS. Organized in a user-friendly format, the topics are grouped in logical categories. In addition, references are provided, encouraging further exploration.

Highly recommended for people with MS, their families, and their healthcare providers."

—Nancy Holland, RN, MSCN, EdD, for **InsideMS**.

