



WORKING WITH MS

Living Well with Multiple Sclerosis



Tracey, diagnosed in 2005



National
Multiple Sclerosis
Society

Working with MS is one in a series of workbooks entitled *Living Well with MS*. This series is written for — and by — people who have been living with multiple sclerosis (MS) for some time. Please contact the National MS Society's MS Navigator® at 1-800-344-4867 (1-800-FIGHT-MS) for information about other workbooks in this series.

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The Society's mission is: We mobilize people and resources to drive research for a cure and to address the challenges of everyone affected by MS.

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INTRODUCTION

The symptoms of MS commonly appear in early adulthood, at a time when young men and women are forming their own households and establishing themselves in their careers. While the initial symptoms might not interfere with work activities to any significant degree, they have the potential to worsen or change over the years. If, and when, the disease becomes more debilitating, it is likely to require some change or adaptation in the working life of the person with MS. Like any life transition, such change can be stressful and difficult.

People tend to react to the impact of MS on their work activities in a variety of ways. Initially, a person might simply try to ignore or defy the MS. While this strategy can work fairly well for those whose symptoms remain mild or sporadic, it may not work as well for those whose symptoms become more severe. At that point, some people find they are struggling so hard to ignore their symptoms, that they have no energy left to do their job. They may also put so much effort and energy into working that they have little left with which to pursue other important personal or family responsibilities.

Working with MS helps people think about career-related options whether they are changing the kind of work they do, returning to employment after being absent for a while, or attempting to maintain a job by accommodating MS symptoms. Disability-related retirement is the subject of a separate workbook in this series.

Like other workbooks in the *Living Well* series, *Working with MS* contains a variety of exercises; some are questions for you to think about or discuss with other people, while others suggest activities to perform or write about in a private journal. You can use the workbook on your own as a guide for personal reflection and problem-solving, or as a shared activity with your family or self-help group. You may prefer to allow yourself time for personal reactions to the ideas and suggestions before talking about them with others.

However you choose to use this workbook, keep in mind that the issues it raises are complex and challenging. Your thoughts and feelings about them may change from one week to the next, depending on your work situation and the symptoms you are experiencing. If you are using the workbook alone, you might want to take a week or two to consider each exercise, making notes of your reactions so you can refer back to them at another time. Those who are using it within a self-help group are advised to allow at least one meeting for each exercise so that group members have time to share their thoughts and feelings.

You may find that some of the exercises in this workbook raise questions or concerns that you wish to explore in greater depth than feels comfortable with family members or your support group. Vocational rehabilitation counselors (see p. 20) can help you explore your employment goals, and guide your efforts to achieve those goals. In addition, a therapist who is knowledgeable about chronic illness and disability can help you work through the feelings of loss, anger and grief associated with changes in your working life.

Work, whether it is paid, household-related, or volunteer, can — and should — be positive and fulfilling. These exercises are designed to address your experience, no matter which kind of work you do. The objectives of this workbook are to help you:

- Explore your personal feelings and attitudes about work and career
- Identify your skills, needs and abilities
- Find resources that might assist you in your work efforts
- Develop your own strategies for working more comfortably with MS

EXERCISE A

What are your attitudes about work?

Ask yourself the following questions about the meaning and importance of work in your life, keeping in mind that there are no right or wrong answers to any of them.

1. How do you define the word “work”?

2. What about the word “career”?

3. And the word “job”?

4. Does work have to be paid in order for you to consider it real or valuable?

Yes No

Please explain:

5. If someone asked you to describe yourself, would you be likely to talk about your work?

- Yes No

Please explain:

6. If someone asked, “What do you do?” would you talk about (*check all that apply*):

- your profession?
 your job?
 your hobbies?
 your daily activities?
 your studies?
 your marital or family status?

7. Whether or not you are currently employed for pay, do you define yourself in terms of work?

- Yes No

Please explain:

8. What aspect of your work gives you the most satisfaction?

9. What reasons for working are most important to you?

The role of work

These questions may have led you to explore the role that work, be it paid, volunteer or household-related, has played in your career. As used in this workbook, the word “career” does not necessarily mean a profession or series of paid jobs. Rather, the word refers to all the different kinds of work performed in the course of a person’s lifetime.

Most people work to keep food on the table and a roof over their head. Other pursuits and other purposes, however, can motivate the many kinds of work done in the course of a career. Work can serve economic, social and psychological purposes. For example, it can provide the opportunity to form social relationships. It can help build feelings of pride and confidence, and a sense of accomplishment. Work can even help to shape a person’s identity or sense of self.

For those of us with MS, the disease can affect our careers in many ways, some of which may seem drastic, even devastating. If, however, we try to look at a career as all of the different kinds of work that shape the course of a person’s life, rather than simply progress up a particular professional ladder, we may view the situation a little differently. We may find, after all, that there is room for MS in a working life.

Sonia’s experience

Sonia is a 35-year-old, divorced woman who teaches first grade. She was diagnosed with MS eight years ago, following an episode of blurred vision and weakness on her right side.

While Sonia’s initial symptoms did not prevent her from teaching, they have gradually worsened over time. Since her most recent exacerbation, about two months ago, Sonia has been on medical leave from her job. She continues to experience weakness on her right side that makes walking difficult and extremely tiring, and interferes with writing and other manual tasks (e.g., helping with 25 sets of buttons, zippers and shoelaces). Her vision periodically becomes blurry, and she has occasional bouts of dizziness.

Sonia knows there is no way to predict the degree to which her current symptoms will improve. Nevertheless, she needs to decide when and how she will resume her teaching responsibilities. Because Sonia supports herself on the salary she earns from teaching and receives good health benefits from the school district, she is determined to remain employed in some capacity until retirement age. In addition, she loves being a teacher and would miss her contact with the children.

Sonia's most recent exacerbation has caused a major and painful disruption in her career. She is eager to return to work, but realizes that she can no longer manage the many physical demands involved in teaching young children. In order to continue teaching, she will need to develop a broader vision of herself as an educator. Such a change does not happen overnight. Indeed, it may take Sonia a while to deal with her situation and feel less overwhelmed. She needs time to mourn the loss of her ability to manage a classroom of young children. She decides to join a self-help group sponsored by the National MS Society, where she can get to know others who might be encountering some of the same employment issues.

At the self-help group, Sonia meets Peter, who is also dealing with the impact of MS symptoms on his work. Although Peter and Sonia are in different stages of their careers, facing different choices, they are able to find ways to help each other manage the changes that MS is bringing to their working lives.

Peter's experience

Peter, who was diagnosed with MS over 20 years ago, is 56 years old. For several years, he has been a production manager in a manufacturing company that makes medical equipment. This job requires Peter to manage a large staff that is spread throughout one whole floor of the plant. Although Peter has experienced several relapses over the course of his career, he has always recovered sufficiently to be able to maintain his job. Recently, however, Peter has begun to experience severe fatigue as well as bladder and bowel symptoms. When he's particularly fatigued, his walking becomes slow and somewhat unsteady. By the end of a working day, he has little energy left to do anything but go to bed and try to get ready for the next day.

"I came to the self-help group to figure out how to work effectively until I reach retirement age," Peter tells Sonia. "My wife and I both depend on the health benefits provided by my job, and I would hate to leave this company after putting in so many years there. I love my job, but it wears me out. I never have any energy to do things with my wife or take care of things around the house. I just can't keep going at the same pace."

MS has knocked Peter and Sonia for a loop. How can they respond to the changes brought about by MS in ways that will allow them to carry on with the careers that have given them satisfaction in the past? Let's examine some coping strategies.

Identifying the things you enjoy about your work

Both Peter and Sonia have always loved their work. They decide that it would be useful to list the things that have been enjoyable and satisfying about their respective careers. At the suggestion of the self-help group leader, they each start a journal and arrive at the lists below:

Sonia's list

1. Working with young children
2. Belief in the value of education
3. The creativity, energy and patience required to be a good teacher
4. The sense of achievement that comes from watching the children learn
5. Pride in the evolution of the school's programs and curriculum
6. The teamwork and camaraderie among the teachers in the school
7. Financial independence

Peter's list

1. The importance of the merchandise the company makes
2. The management skills required to get everything out on time
3. The sense of control over production
4. Financial recognition
5. Working with others for a common purpose
6. Solving problems to achieve the company's goals
7. The satisfaction of a job well done

EXERCISE B

What aspects of work give you pleasure?

Think about your own career. Keep in mind that “career” refers here to all the different kinds of work you may have done as a paid employee, a volunteer, a student or a member of a household. List what you have most enjoyed about the work. You do not have to think about the effect that MS may have had on your capacity to perform a particular kind of job. Just list the elements of your career you have found most satisfying. Remember that the work need not be paid in order to appear on this list.

1. _____
2. _____
3. _____
4. _____
5. _____
6. _____

Acknowledging what you may have lost; considering what you still can do

At the next self-help group meeting, Sonia is feeling down. Listing what she enjoys about teaching has led her to dwell on the ways that MS has affected her abilities in the classroom. She shares with the group the fact that writing the list has left her feeling sad.

“It’s very hard to think about having to change the way I work,” she tells the group.

“Wait a minute,” responds Peter. “You may not be able to maneuver around the classroom the way you used to, but you still have the interest and drive to be a good teacher. You don’t have to do things exactly the way you’ve done them in the past to be effective in the classroom. If I were you, I would take another look at my list.”

EXERCISE C

What abilities has your MS affected?

Try to follow Sonia and Peter's example. Look at the list you created in *Exercise B*. Review the things you enjoy about the work you do now or have done in the past. Respond to each item on the list with a sentence or two, noting whether MS has had an impact on your abilities.

1. _____
2. _____
3. _____
4. _____
5. _____
6. _____

If your ability to carry out a particular activity is unchanged, celebrate that fact. If your capacity has diminished, note how. Have you allowed yourself to grieve over that change?

Do you have any new ideas about work, or about your career, because of the change?

Thinking about new possibilities & transferable skills

Sonia begins to realize that her many years of teaching have left her with a wealth of valuable skills. She wants to discuss them with her principal to see how they might be put to best use within the school. She suggests to Peter that they write resumes reflecting their talents, skills and experience. “I know we aren’t looking to leave our respective employers, but writing a resume might help us assess our skills and accomplishments, and maybe even point us in a new direction in case things don’t work out where we are now.”

Note: Writing a resume is a significant undertaking. It is common to have a different version for each job for which you apply. Search online for resources on resume-writing.

Sonia's talents & skills

1. Knowledge of childhood development
2. Teaching experience and expertise
3. Ability to work well with other teachers
4. Expertise in curriculum development
5. Creativity, patience and a sense of humor
6. Understanding of group dynamics
7. Classroom administration and management skills

Peter follows Sonia with his own list of skills:

Peter's talents & skills

1. Knowledge of requirements for company positions
2. Familiarity with production scheduling
3. Management skills
4. Ability to communicate effectively
5. Team-building aptitude
6. Experience as a problem-solver
7. Knowledge of the industry, products and vendors

EXERCISE D

What enables you to do the work you enjoy?

List the skills and talents that MS has not changed:

1. _____
2. _____
3. _____
4. _____
5. _____
6. _____

Both Sonia and Peter realize that their skills and experience could be applied to a broad variety of work, but neither is quite sure how to proceed. “I don’t know what to do,” says Sonia, once her resume is written. “Should I talk to my principal about accommodations that might help me continue with my present job? If I moved to a classroom in the new part of the building, I could avoid the stairs and use a motorized scooter to conserve my energy. If the administration would provide me a part-time teacher’s aide to handle the photocopying and other non-teaching chores, I’d have more energy to use with the children.”

“Maybe I should also look into teaching children who are somewhat older so that I wouldn’t need to be involved in so many physical activities with them. My job would certainly be less tiring if the children were more independent and I didn’t have to provide so much hands-on assistance. If I were teaching fifth or sixth grade I could give them printed handouts rather than having to write on the board all the time. Maybe I could even ask the school to help me get a voice-activation program for the computer so that I could produce the handouts without having to type them by hand.

I suppose I could also think about taking the few additional courses I would need to transition into guidance or administration. By going that route, I could avoid the physical stress and strain of the classroom altogether. I'm not sure what to do. I was starting to feel as though I had no choices left, but now I feel as though I have too many."

"I know what you mean," Peter responds. "Writing that resume has made me realize how many different kinds of work I'm qualified to do, even at the same company I've been employed by for all these years. I've been thinking about transferring over to the human resources department. I certainly know what it takes to get the production job done. Maybe I could interview candidates for positions in my current part of the business. Or perhaps there's another job in Human Resources that would tap some of my skills.

I am a pretty effective communicator who knows the business very well. Maybe I could do training for the company. I have good management and team-building skills I could pass on to others. Of course, maybe what I really need to do is ask for some accommodations from the company that would make my current job easier, like a more flexible schedule and an office closer to the elevator and bathroom. I could also use an intercom system to cut down on long walks to see my staff. Changes like that might allow me to stay in my present job, MS or no MS. That's probably my best option."

EXERCISE E

Can your skills be used differently or transferred?

Now think about other kinds of work in which you could apply your experience in the event that MS were to interfere with ways you currently utilize your skills. For each of the skills you listed in *Exercise D*, complete the following sentence.

If MS changed my ability to _____, I could use my experience to _____ instead.

Members of the self-help group, who have been listening to Sonia and Peter talk about what their next steps should be, help them realize that the initial step is to figure out what they want most from their work. Once Sonia and Peter have established their individual career goals, they will be able to start pursuing them with greater confidence.

Sonia decides to list the top five or six things she hopes to gain from her work, and then rank them in the order of their importance to her. She describes in her journal what each item means to her, and how it compares to each of the other important items.

She talks at length to her friends and colleagues and, of course, to her self-help group, about the process of defining her career goals. Sonia finally arrives at the following list:

1. To continue working until retirement age
2. To remain a classroom teacher as long as possible
3. To continue working at the elementary school level as long as possible
4. To inspire children to learn and develop their skills and talents
5. To be recognized, financially and/or otherwise, for my efforts

Peter already knows that he wishes to remain at the same company until retirement. Nevertheless, he also has many issues to consider before he can identify the goals he hopes to achieve through his work. After applying himself to the task at hand, he comes up with the following list:

1. To remain secure until retirement
2. To maintain my salary
3. To contribute to the functioning of the company
4. To keep my skills in good shape
5. To pass those skills along
6. To be remembered as a positive force in the business

A comparison of Peter's list to Sonia's reveals different priorities that are appropriate to their respective ages and career stages. Peter, who is closer to retirement age, is most concerned with maintaining the status quo. He is willing to make some changes in his working life, but does not want to do anything drastic. Although he might consider changing his role at the company, his desire to maintain his salary may dissuade him from making any major changes. His most important task may be to identify the best way to remain effective in his current job.

Sonia, on the other hand, needs to plan for an uncertain future even while she is working to make her present job easier and more accessible. She is willing to pursue some further training in preparation for a time when she might be unable to manage in a classroom of elementary school children. In the meantime, she is also planning to talk to her principal about moving to an accessible part of the school building and possibly to an older grade, and getting a part-time teacher's aide.

EXERCISE F

What are your main goals?

Make your own list of what you wish to gain from your work. Place a goal on your list whether or not you are meeting it at this stage in your career. Rank the goals in order of their importance to you. Write in your journal, or in the space below, about each item on your list and its importance.

1. _____
2. _____
3. _____
4. _____
5. _____
6. _____

You may have something in common with either Sonia or Peter. It could be that you want, or need, to make a major career change. Perhaps financial compensation is the most important factor. Maybe you are already engaged in work that you love, and simply need to figure out how to keep on doing that work. It could be that you want to figure out what sort of volunteer work would be best for you to do. Whatever your situation may be, the intent of this exercise is to help you to identify and prioritize your needs and goals.

EXERCISE G

What work situations would be best for you?

Answer the following questions to further refine your needs and preferences about work:

1. Would you rather be self-employed or work for a company or organization of some kind?

What are your reasons?

2. Would you prefer to report daily to an office, job site, or other workplace or would you rather operate out of your home?

What are your reasons?

3. Is a flexible schedule important to you?

- Yes No

If so, please explain:

Enlisting the help available to you

In the course of exploring the many career options open to her, Sonia learns that every state in the country has offices of vocational rehabilitation that help people with disabilities remain in, or return to, productive work. She contacts the National MS Society to obtain the phone number of the nearest office, and makes an appointment to see a vocational rehabilitation counselor. Sonia brings her resume to the appointment and tells the counselor her story. Following a lengthy evaluation process, she is approved for vocational rehabilitation services.

Rehabilitation offices provide different services, depending on the needs of their clients. Sonia and her counselor write a detailed plan for Sonia, called an Individualized Written Rehabilitation Plan (IWRP). The plan specifies goals and objectives for Sonia, the most important of which is that she pursue her plan to take additional courses to prepare her for work outside the classroom in the event that increasing disability makes her current work impractical. Even if Sonia never needs to give up elementary school teaching, she will be more secure knowing that she has created a contingency plan for herself.

The IWRP also outlines the accommodations Sonia currently needs in order to continue in the classroom for the foreseeable future. The counselor will assist Sonia in finding out whether the Department of Vocational Rehabilitation will cover any of the costs associated with the motorized scooter or other assistive devices she may need in order to continue her teaching responsibilities.

The rehabilitation counselor explains to Sonia that the Americans with Disabilities Act (ADA) that was passed in 1990, is a federal law that prohibits discrimination against people with disabilities in employment, transportation, public accommodation, communications, and activities of state and local government.

Title I of the ADA states that an employer with 15 or more employees cannot discriminate against qualified applicants and employees on the basis of disability. Any employee who has the qualifications to perform a particular job is entitled to reasonable accommodations to support his or her efforts to carry out that job. A reasonable accommodation is defined as one that would facilitate the individual's job performance without causing undue financial hardship for the employer. While it is the responsibility of the employee to request the necessary accommodations from his or her employer, the employer and employee work together to implement accommodations that are reasonable and workable for both of them.

The vocational counselor also tells Sonia about the Job Accommodation Network (JAN), an international consulting service that provides information about job accommodations and the employability of people with functional limitations.

Sonia shares the information she has gained with Peter, who also benefits from a visit to his local vocational rehabilitation office. His IWRP includes the goal of exploring accommodations that would make it possible for him to continue to be effective in his present job. In addition to the accommodations Peter had already thought of on his own, the counselor urges Peter to request a disabled parking space and consider using a motorized scooter on the job. The scooter would significantly reduce his fatigue by allowing him to supervise his staff without having to walk at all.

The self-help group leader suggests that Peter and Sonia contact the National MS Society to request a copy of "The Win-Win Approach to Reasonable Accommodations," a booklet that outlines the steps involved in requesting reasonable accommodations from one's employer. Armed with this information and the suggestions from the vocational rehabilitation counselor, Peter and Sonia feel better prepared to discuss possible job accommodations with their employers.

For a listing of these and other employment-related resources, refer to the RESOURCES section at the end of this workbook.

CONCLUSION

Both Peter and Sonia are still shaping their careers. Peter has asked the human resources department of his company for reasonable accommodations that will allow him to continue to do his job as well as he has always done it. The department is working with him, and with the Job Accommodation Network, to decide how best to accommodate him on the job. Peter's request for a more flexible schedule has been met, and his concerns about job security until retirement have been addressed. He is delegating more duties to his staff, while remaining productive on the job. Both Peter and his supervisors are certain that he will continue to make a meaningful contribution until he retires.

Sonia has begun teaching a fifth-grade class in the new wing of the school. While she misses the younger children, she is discovering that working with older children gives her the opportunity to use her skills and creativity in a variety of new ways. With the help of a part-time classroom aide and the use of a motorized scooter, she has enough energy to meet her responsibilities in the classroom and take an evening course two days a week.

Both Peter and Sonia set career goals for themselves. Peter's goal was to remain in his present job in manufacturing. Sonia's goal was to continue in the classroom while beginning to prepare for a time when she might not be able to handle a classroom job. Both of their careers are still evolving. Both of them have met their goals and found fresh hope, ambition, security and fulfillment in their work, because they have learned to work with their MS.

Perhaps, as you have performed the exercises in this workbook, you have moved closer to formulating your own career goal. As you finalize that goal, whether it be to stay with your present work or change your field of endeavor, may your efforts meet with great success. Keep in mind that there are a variety of resources available to help you in your efforts.

SUGGESTED READINGS & RESOURCES

Books

Holland, N., Murray, T.J., Kalb, R. (2007). *Multiple Sclerosis for Dummies*. For Dummies Publishing.

Jackson, T. (2004). *The Perfect Resume*. Broadway.

Kalb, R (2011). *Multiple Sclerosis: The Questions You Have — The Answers You Need*. Demos Health Publishing.

Rumrill, P. D. Jr., & Nissen, S. (2008). *Employment Issues and Multiple Sclerosis*. Demos Health Publishing.

Schapiro, R.T. (2007). *Managing the Symptoms of Multiple Sclerosis*. Demos Health Publishing.

Schwarz, S.P (2006). *Multiple Sclerosis: 300 Tips for Making Life Easier*. Demos Health Publishing.

Szymanski, E. & Parker, R. (2003). *Work and Disability: Issues and Strategies in Career Development and Job Placement*. Pro-Ed.

The National MS Society has an extensive library of resources about MS, including publications about symptom management and the day to day challenges of living with the disease. The publications listed below are available at nationalMSsociety.org/brochures or 1-800-344-4867 (1-800-FIGHT-MS).

Brochures

Employment Issues:

A Place in the Workforce

Focus on Employment

Information for Employers

Should I Work? Information for Employees

The Win-Win Approach to Reasonable Accommodations

Managing Major Changes:

ADA & People with MS

Adapting: Financial Planning for a Life with MS

Managing Specific Issues:

Fatigue: What You Should Know

Solving Cognitive Problems

Vision Problems: Basic Facts

Staying Well:

Managing MS through Rehabilitation

Online

Can Do Multiple Sclerosis Webinars

mscando.org

Career Crossroads

nationalMSsociety.org/careercrossroadsDVD

Live Fully Live Well

nationalMSsociety.org/LiveFullyLiveWell

MS In the Workplace

ntl.ms/MSintheWorkplace

MS Learn Online Series

nationalMSsociety.org/mslearnonline

Multimedia Library: DVDs

nationalMSsociety.org/DVDs

Online Classes

nationalMSsociety.org/onlineclasses

Agencies & Organizations

ABLEDATA

(800) 227-0216

abledata.com

ADA TAP Program

(800) 514-0301 (voice); (800) 514-0383 (TTY)

ada.gov/taprog.htm

Alliance for Technology Access

(800) 914-3017

ataccess.org

American Foundation for the Blind (AFB)

(800) 232-5463

afb.org

American Printing House for the Blind

(800) 223-1839

aph.org

Can Do Multiple Sclerosis

(800) 367-3101

mscando.org

Disability Rights Education & Defense Fund (DREDF)

(510) 644-2555

dredf.org

Equal Employment Opportunity Commission

(800) 669-4000; (800) 669-6820 (TTY)
eeoc.gov

The Job Accommodation Network (JAN)

(800) 526-7234
askjan.org

National Association of the Deaf

(301) 587-1788; (301) 587-1789 (TTY)
nad.org

National Board of Certified Counselors

(336) 547-0607
nbcc.org

National Institute on Deafness & Other Communication Disorders

(800) 241-1044; (800) 241-1055 (TTY)
nidcd.nih.gov

National Institute on Disability & Rehabilitation Research (NIDRR)

(202) 245-7640 (Voice/TTY)
www2.ed.gov/about/offices/list/osers/nidrr/index.html

National Library Services for the Blind & Physically Handicapped

(202) 707-5100; (202) 707-0744 (TTY)
loc.gov/nls

National Rehabilitation Information Center (NARIC)

(800) 346-2742; (301) 459-5984 (TTY)

naric.com

President's Committee on Employment of People with Disabilities

(202) 376-6200; (202) 376-6205 (TTY)

access4911.org/president%27s_committee.htm

Rehabilitation Services Administration (RSA)

(202) 245-7488

www2.ed.gov/about/offices/list/osers/rsa/index.html

Small Business Administration

(800) 827-5722; (704) 344-6640 (TTY)

sbaonline.sba.gov

Social Security Administration Office of Disability

(800) 772-1213; (800) 325-0778 (TTY)

ssa.gov

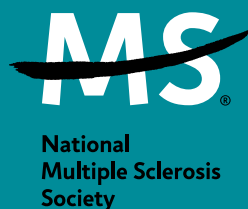
Telecommunications for the Deaf, Inc.

(301) 563-9112; (301) 589-3006 (TTY)

tdi-online.org

The National MS Society is a collective of passionate individuals who want to do something about MS now — to move together toward a world free of multiple sclerosis.

We help each person address the challenges of living with MS through our 50-state network of chapters. The Society helps people affected by MS by funding cutting-edge research, driving change through advocacy, facilitating professional education, and providing programs and services that help people with MS and their families move their lives forward.



For more information:

nationalMSSociety.org

1-800-344-4867 (1-800-FIGHT-MS)