MS & WELLNESS

Living Well with Multiple Sclerosis

Susan, diagnosed in 1995
MS & Wellness 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.

Author:

Janie Brunette, R.N., M.S.N.
Janie Brunette resides in Willard, Missouri. She has been an active volunteer in Mid-America since she was diagnosed with MS in 1981.

Diane Reaves, B.S.
Diane Reaves has co-authored two books on fitness and an instructor training program, and has conducted the program for hundreds of aquatic exercise instructors throughout the U.S. She has also written for magazines, journals and various newsletters.

Editors:

Beverly Noyes, Ph.D.
Rosalind Kalb, Ph.D., National MS Society
Doris Lill, National MS Society

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 World Health Organization describes “health” as the highest level of function and wellbeing a person can attain within the limits imposed by any physical or emotional impairment. This means that it is possible to be healthy even if you have a chronic disease like multiple sclerosis. Whether your MS is causing many symptoms or just a few, you can achieve and maintain health by opting for those health-promoting behaviors that will enhance your functional abilities and wellness. The term “wellness” has come to mean a state of personal health characterized by optimal physical, emotional and spiritual wellbeing.

MS & Wellness is a workbook to use individually or with others. You can use it on your own as a tool for evaluating and monitoring your personal wellness, or as a group activity with family members or your self-help group to share suggestions and ideas to promote personal wellbeing. Like other workbooks in the Living Well series, MS & Wellness contains various exercises. Some consist of questions for personal reflection and/or group discussion; others suggest an activity for you to try, alone or with others.

However you choose to make use of this workbook, keep in mind that wellness is not something to be achieved easily or quickly. Nor is it a fixed goal that can be achieved once and then forgotten. Because it involves many aspects of a person’s physical and emotional life, wellness is a state that we work to achieve on a day-to-day basis. You may find that your responses to the various questions change from one week to the next, particularly if you tend to experience fluctuations in your MS symptoms which interfere with daily living or affect your moods. For some of us, just getting through each day can seem challenging enough without even thinking about other physical, emotional or spiritual needs.

The workbook’s objectives are to:

- Clarify the meaning of wellness and its relevance in your life
- Outline various strategies for achieving and maintaining wellness
- Help you formulate a plan to maintain optimal wellness throughout your lifetime
EXERCISE A

What is the role of wellness in your life?

As a way to begin exploring your attitudes about MS and wellness, ask yourself the following questions:

1. Do you consider yourself to be a healthy person?
   ○ Yes   ○ No
   Please explain:
   __________________________________________________________
   __________________________________________________________
   __________________________________________________________

2. Do you consider yourself to be a well person?
   ○ Yes   ○ No
   Please explain:
   __________________________________________________________
   __________________________________________________________
   __________________________________________________________

3. What role, if any, does MS play in your assessment of your own “health” or “wellness”?
   __________________________________________________________
   __________________________________________________________
   __________________________________________________________
4. If you do not consider yourself to be healthy and well, what would have to change in order for you to alter that opinion?

_____________________________________________________________________________
_____________________________________________________________________________
_____________________________________________________________________________

5. Do you believe you have control over your level of wellness?

☐ Yes ☐ No

Please explain:

_____________________________________________________________________________
_____________________________________________________________________________
_____________________________________________________________________________

6. Are you ready to think about your health and wellness in broader terms than having MS?

☐ Yes ☐ No

Please explain:

_____________________________________________________________________________
_____________________________________________________________________________
_____________________________________________________________________________
Discussion

You may be asking yourself how it is possible to be healthy and well in spite of a chronic illness like MS. There are four main strategies to follow:

- Work with your healthcare provider(s) to manage your MS symptoms, slow disease progression and prevent unnecessary complications.
- Attend to your non-MS healthcare needs via regular medical check-ups and appropriate health screening measures, as well as adequate management of any problems that may arise independent of MS.
- Engage in the same health maintenance and disease prevention behaviors that are recommended for everyone — whether or not they have MS — including good sleep habits, adequate nutrition, proper exercise, and attention to your emotional and spiritual needs.
- Be an educated consumer; stay informed about MS management strategies as well as general health maintenance guidelines for a person in your age group.

The remainder of this workbook will examine these strategies in greater depth.
EXERCISE B

Managing your MS

How do you manage your MS care?

1. Do you see a specialist (e.g., neurologist, physiatrist) for management of your MS, or is your MS managed by your primary care physician?
   - Specialist
   - Primary Care Physician
   - Other

   Notes:

  _____________________________________________________________________________
   _____________________________________________________________________________
   _____________________________________________________________________________

2. Do you see your MS doctor on a regular basis?
   - OR
   - Only in the event of a major problem of emergency?

   Notes:

  _____________________________________________________________________________
   _____________________________________________________________________________
   _____________________________________________________________________________
   _____________________________________________________________________________
3. Do you come to your medical appointment prepared to tell the doctor about any problems or changes you have experienced since the last visit?

☐ Yes ☐ No

Notes:
_____________________________________________________________________________
_____________________________________________________________________________
_____________________________________________________________________________

4. Are you comfortable talking with your doctor about difficult or sensitive topics, such as sexual problems or cognitive changes that you may be experiencing?

☐ Yes ☐ No

Notes:
_____________________________________________________________________________
_____________________________________________________________________________
_____________________________________________________________________________

5. Do you try to keep yourself informed of developments in the management and treatment of MS?

☐ Yes ☐ No

Notes:
_____________________________________________________________________________
_____________________________________________________________________________
_____________________________________________________________________________
Discussion

Because there is no cure for MS at the present time, many people who live with the disease feel that there is no particular reason to see the doctor on a regular basis. Others may resist seeing the doctor because they are afraid he or she will say that the disease is progressing. Still others may think that there’s nothing to be done for MS symptoms, so there’s no need to bother.

Now, however, there are more reasons than ever before to have regular visits with the physician who is helping to manage your MS. First, the doctor’s ability to monitor your disease course, identify symptom progression, provide appropriate treatments and referrals, and prevent unnecessary complications (e.g., osteoporosis, skin breakdown, infections), depends on a thorough examination and the information that you provide during an office visit.

Second, the past decade has seen the development of several new drugs that have been shown to slow disease progression. Your ability to use one of these medications comfortably and effectively, until something even better comes along, will be enhanced by the ongoing support of your healthcare provider(s).

Third, the appropriate use of effective symptom management strategies can help to promote comfort and function, and prevent complications. Whether your MS care is provided by your primary care physician or a specialist, it is important to see your doctor at least once a year.
EXERCISE C

Attending to your non-MS healthcare needs

How do you manage your general health?

1. Have you had a complete physical examination within the last eighteen months?
   - Yes  - No

2. Have you undergone all of the medical tests and screening procedures recommended for someone in your age group (e.g., blood tests, chest x-ray, mammogram, prostate exam, colonoscopy, dental exam)?
   - Yes  - No
   
   Make a note here of the dates of your most recent medical tests and screening procedures:
   
   ________________________________________________________________________________
   ________________________________________________________________________________
   ________________________________________________________________________________
   ________________________________________________________________________________
   ________________________________________________________________________________

3. Are the offices of your healthcare provider(s) sufficiently accessible for you to be able to receive complete examinations?
   - Yes  - No
4. Is one of your physicians or other healthcare providers (e.g., primary care physician) acting as the coordinator for your care?
   - Yes
   - No

5. Do your healthcare providers maintain any kind of contact with one another?
   - Yes
   - No

6. Are you prepared to take responsibility for coordinating your own care if your physician(s) are not doing so?
   - Yes
   - No

7. Do you provide each of your doctors with a complete list of the medications you are taking and the treatment you are receiving from other healthcare providers?
   - Yes
   - No

After you have answered these questions, make a list of all of your healthcare needs that are unrelated to MS, and indicate how recently you have seen a doctor or other healthcare provider for each of these needs.

________________________________________________________________________________
________________________________________________________________________________
________________________________________________________________________________
________________________________________________________________________________
________________________________________________________________________________
Discussion

People who are living with a chronic illness like MS may tend to focus their attention solely on the illness, to the neglect of their general health. MS can prove to be so time-consuming and expensive for some people that they don’t want to think about any other medical problems. Or, they may believe that having MS is enough for any one person to deal with, so there’s no reason to think they will ever get anything else. Some people even hope that having MS will protect them from getting anything else. However, MS does not protect a person from other diseases or conditions, and people with MS need to pay as much attention to preventive healthcare as anyone else does.

Unfortunately, physicians and other care providers may also tend to neglect the general healthcare needs of those with a serious chronic illness. Due to the prevalence of HMOs and other managed care organizations in today’s healthcare system, medical care tends to be more fragmented than it used to be. People with MS may be referred by their primary care physician to a neurologist for management of their MS. Since MS might require several visits to the neurologist over the course of a year, and since people with MS are often unsure which of their problems are related to MS and which are not, they may begin to think of the MS specialist as their principal healthcare provider. As a result, visits to the primary care physician become far less frequent.

While it is reasonable to expect your neurologist to stay informed about all of the newest advances in MS treatment, you should not expect that same doctor to be solely responsible for your general health and wellbeing. The MS specialist generally expects that your cardiovascular, gender specific, emotional and other general healthcare needs will be addressed by your primary care physician or other specialists. As a result, non-MS healthcare needs may go unmet if you do not see your primary care physician on a regular basis or are referred to specialists. It is important to maintain an ongoing relationship with a general practitioner, internist or nurse practitioner who can help you monitor your general healthcare needs.
EXERCISE D

Health maintenance & disease prevention

Taking a look at your lifestyle

The following questions are designed to help you think about some important lifestyle behaviors that can have an impact on your overall health and wellbeing.

1. Are you getting enough sleep to meet your current needs?
   - Yes  
   - No

   If not, why not?
   - My need for sleep has increased.
   - My sleep patterns seem to have changed.
   - I have difficulty falling asleep or staying asleep.
   - I am taking medications which increase my fatigue or sleepiness.
   - My sleep is interrupted by trips to the bathroom or uncomfortable symptoms such as leg spasms and cramps.
   - Other

2. Have you made yourself aware of the recommended nutritional guidelines for a person of your age and gender? For example, do you:

   Choose a diet that is high in grain products, vegetables and fruits, moderate in sodium (salt) and sugar intake, and low in fat, saturated fat and cholesterol?
   - Yes  
   - No
Consume at least 1000 mg of calcium per day (and more if you have significant mobility problems, take steroids or are a postmenopausal woman who does not take estrogen)?

☐ Yes  ☐ No

3. Do you perform regular breast or testicular exams as instructed by your physician?

☐ Yes  ☐ No

4. Have you discussed with your physician the appropriate types and amounts of exercise for someone in your age group with your particular MS symptoms?

☐ Yes  ☐ No

5. Have you made time in your life for the relationships and activities that meet your emotional and spiritual needs?

☐ Yes  ☐ No

6. Do you have a repertoire of stress-management techniques to help you deal with the many day-to-day stresses that life presents?

☐ Yes  ☐ No

If so, what are they?

_____________________________________________________________________________
_____________________________________________________________________________
_____________________________________________________________________________

7. Do you smoke?

☐ Yes  ☐ No
Discussion

The point of this exercise is to remind you that a healthy lifestyle is important for all of us. There may be no cure for MS at this time, but there is still reason to live a life of wellness while we are waiting for that cure. We can choose to engage in behaviors that support our efforts to live with MS and enhance our overall health and wellbeing. Let’s look at them one at a time.

Managing fatigue

Fatigue is perhaps the most common of all MS symptoms. If you are experiencing a significant amount of fatigue, it is important to discuss it with your physician so that he or she can help you identify the sources of your fatigue, and make appropriate recommendations for its management. In addition to making the determination whether a medication (e.g., amantadine, Provigil® or Prozac®) might reduce your MS-related fatigue, your physician will want to look into the medications you are currently taking, your current sleep patterns and the amount of exercise you are getting.

Many of us with MS take a variety of medications to address our MS symptoms. Some of these medications have the side effect of causing fatigue or sleepiness. Therefore, your physician may want to adjust the types or dosages of medications you are taking in order to minimize your tiredness. Your physician will also recommend treatment strategies for any symptoms such as spasticity, bladder problems or depression that might be interrupting your sleep. In addition, it will be important for your physician to assess the amount of exercise you are currently getting. Although many of us believe that exercise is not possible or recommended for people with MS, research indicates that a moderate amount of exercise can actually increase energy and reduce MS-related fatigue.

In spite of these interventions, you may find that fatigue continues to be part of your life with MS. In that event, it will be important for you to acknowledge its impact and find a place for it in your wellness lifestyle. If you have had the diagnosis for some time, you have probably already learned a few tricks to manage life with fatigue. Perhaps you have learned to conserve your energy for the things that are most important to you, and found a way to plan your day so that it runs out before you do. You may also have identified the periods in the day when you are most fatigued, and learned to build in short rest periods. You may even have discovered that it is sometimes better to give in to your fatigue than to struggle against it. People who don’t have MS allow themselves to feel exhausted and take a “time out” occasionally; why shouldn’t you?
EXERCISE E

Making use of an energy diary

Using the worksheets in Appendix A (pp.28–29), keep an energy diary for one week. This exercise will help to clarify your overall energy pattern and enable you to plan your periods of activity and rest more effectively. As an alternative to a written diary, you can use a voice recorder and record your responses at different times throughout the day.

Do you notice any patterns in your diary? Are you more fatigued during some periods of the day than others? Do naps or rests allow you to regain your energy? Try to figure out how to schedule your activities in ways that minimize the fatigue and maximize your energy. You might also want to consult with an occupational therapist about tools and strategies for conserving energy in your home and at your workplace.

Keep in mind that pushing yourself too long and too hard during periods of high energy can increase your fatigue and lengthen the time it takes you to bounce back. Pay attention to your body’s early signs of fatigue so that you can pace yourself more effectively, and take a break before you reach the point of exhaustion.
EXERCISE F

Making exercise a part of your life

What is your current exercise routine?

1. Do you currently have a regular exercise routine?
   ○ Yes   ○ No

   If so, list the types of exercise you most enjoy.
   __________________________________________________________
   __________________________________________________________
   __________________________________________________________

2. People exercise (or think they should exercise) for a variety of reasons. Which of the following reasons are closest to your own:
   ○ Fitness
   ○ Weight reduction
   ○ Recreation
   ○ Symptom relief
   ○ Stress
   ○ Competition
   ○ Other
3. Have your exercise patterns changed in recent months?
   ○ Yes   ○ No

   If so, what was the reason for the change?

   _______________________________________________________________________________
   _______________________________________________________________________________
   _______________________________________________________________________________

4. Are you concerned about the impact of exercise on your MS symptoms or the progression of the disease?
   ○ Yes   ○ No

5. Have you been told by others that you should stop exercising now that you have MS?
   ○ Yes   ○ No

   If so, what were their reasons?

   _______________________________________________________________________________
   _______________________________________________________________________________
   _______________________________________________________________________________

6. Make a list of daily chores or activities that involve physical activity or exercise (e.g., vacuuming, raking leaves, walking your children to the bus stop, walking to the train station).

   _______________________________________________________________________________
   _______________________________________________________________________________
   _______________________________________________________________________________
Discussion

Exercise is an essential wellness behavior. It has been shown in the general population to reduce the risk of heart disease, diabetes, osteoporosis and certain types of cancer, help with weight control, increase energy levels, reduce stress and improve overall quality of life. Many people with MS, however, are confused about the role exercise should be playing their lives. Some neglect this important wellness activity because they are concerned that it will increase their fatigue or make the disease worse. Others try to engage in very vigorous exercise in an effort to prevent disease progression or reverse the demyelination that has already occurred. It is important to understand what exercise can and cannot do for you.

Multiple sclerosis is a disease of the nervous system — not a disease of the muscles. Because demyelinated nerve fibers do not communicate well with the muscles, however, wasting (or atrophy) of the muscles can occur from lack of use. Moderate exercise can help keep your muscles toned and healthy, strengthen muscles that have become weakened, enhance flexibility and provide the same general health benefits that it provides for everyone.

In a study funded by the National MS Society, an aerobic exercise program consisting of three supervised training sessions every week for 15 weeks provided significant benefit for individuals with mild to moderate disability. The study participants demonstrated improved strength and fitness, as well as decreased body fat. In addition, they experienced improvement in other factors relating to quality of life, including their levels of depression and anger.

*Exercise cannot prevent or slow the demyelination that is caused by MS. Nor can it reverse the demyelination that has already occurred, or alter the long-term course of the disease.*

Your physician can help you identify which type(s) of exercise would be most beneficial for you. He or she may refer you to a physical therapist (PT) or occupational therapist (OT) who can design an exercise program that is tailored to your needs and abilities. In addition, the Society can refer you to suitable exercise programs in your area. In designing your exercise program, try to choose pleasurable activities. It will be far easier for you to make a habit of a routine you enjoy. In addition, try to stay open to the possibility that you may need to adapt your exercise program to any changes that occur in your body. Your physician, PT or OT can suggest ways to modify your exercise activities and/or schedule to meet your changing needs.
Regardless of the type of exercise program you choose, it is important to:

- Consult with your physician before you begin
- Start gradually, avoiding strain and allowing periods of rest
- Exercise in a cool environment to avoid becoming overheated
- Drink plenty of water before, during and after exercise

In case you are feeling overwhelmed at the thought of adding exercise to your life, try to remember that exercise can take a variety of forms. The Society, organizations like the YWCA and YMCA, and city and county pools, often sponsor aquatic exercise classes. Aquatic exercise does not require the ability to swim, although swimming is another form of exercise that is often recommended for people with MS. Because the buoyancy and cooling effect of the water provides an exercise medium that is suitable for people of all levels of fitness and most levels of disability, you may be able to benefit from aquatics well into the future.

*Note: The National Multiple Sclerosis Society recommends that the pool temperature for people with MS be no more than 84 degrees. Many public pools are warmer, particularly if they also offer arthritis programs. Since higher water temperatures can temporarily increase your symptoms, it is important to ask about the water temperature before joining an aquatics program.*

For many, the social aspect of exercising in a class with others adds a component that goes beyond the rewards of physical exertion. If you live in an area that does not offer aquatics programs, you may want to consider other exercise options that involve groups. You might find exercise classes through adult education programs, the Society, or a local college or fitness club. You could also take advantage of free demonstration classes that are offered in some communities. Sampling different exercise techniques will give you a chance to discover the basics of different exercise activities and decide which of them is best for you. Remember, however, to consult with your physician before starting any new exercise regimen, and talk to the instructor about your medical condition prior to joining a class. This will help to ensure that the program is appropriate to your level of ability, and able to accommodate any variations you may need from time to time.

An advanced aerobics class is not likely to meet your needs if you tire easily or have not exercised in a while. On the other hand, an introductory yoga or Tai Chi group might be just what you need to build a stronger awareness of your body. Other good exercises you might continue to enjoy include walking, light jogging and bicycling.
Perhaps you prefer to exercise alone. There are many advantages to solo workouts. You are not limited by a specific class schedule. You can choose an activity to pursue in the privacy of your home when your body feels most ready. Some activities, such as Tai Chi or yoga, can be learned in a class and then used on your own. Various types of exercise videos are also available at a reasonable cost or for rental, allowing you to make use of them at the time of day that works best for you. Contact the Society about exercise videos specifically designed for people with disabilities.

Keep in mind, as well, that many enjoyable hobbies have a healthy physical component. Are there any favorite activities you have not tried since you were diagnosed with MS? Did you stop doing them because you were physically unable to continue, or only because you thought you were? Re-examine an activity that you loved and practiced in the past; with a little creativity, you may be able to take it up again in a new and satisfying way.

Perhaps you always loved to garden. You might find that a special scooter for the yard would enable you to engage in most, if not all, of your favorite gardening activities. If you were an active runner, you might be a natural for one of the various forms of walking-for-exercise, even walking in water. If you always loved to dance, you may want to reconsider some steps you never bothered to learn when you were burning up teenage calories at school dances. The many classes that are offered for adults (couples or singles) can be a great way to meet new friends with a common interest. Try to rethink what you love to do; many of your favorite activities may still be possible if looked at in a different way.

The physical abilities of people with MS vary widely. Some are able to run for miles a day, while others are quadriplegic or use powered wheelchairs. The optimal exercise program for each person is different. It is important to pick an exercise activity that suits your functional abilities and set personal goals that are healthy and reasonable. This will enable you to take pride and satisfaction in the progress you make today rather than comparing yourself to others, or even to the way you used to be before MS came along. The research indicates that, although levels of improvement may vary, most people with MS can improve their fitness and strength through exercise.

No matter what type of exercise program you choose, it will be important for you to build your stamina and strength gradually in order to prevent strain and injury. A painful injury may discourage you from future activity, cause increased spasticity or lead to more weakness. With the help of your health professional and some of the ideas in this section you should be able to find the right approach for your own wellness plan.
EXERCISE G

Choosing an exercise program for you

Make a list the physical activities you enjoy:

1. 
2. 
3. 
4. 
5. 
6. 
7. 
8. 

Do not omit anything just because MS has made it difficult to do. Remembering what you liked about them may help you begin to find ways of adapting them to any physical changes you have experienced. Research ways online to pursue some of these physical activities. This will help you find ways to incorporate enjoyable exercise into your life of wellness.
List three different options for exercise programs you might follow:

1. _____________________________________________________________________________
2. _____________________________________________________________________________
3. _____________________________________________________________________________

Now, choose the one that appeals to you most, and get started!

**Maintaining a healthy diet**

Although various diets have been touted over the years as cures or treatments for MS, none has been shown in a controlled study to have any significant impact on symptoms or disease course. The only diet that is recommended by MS specialists for people with MS is the same high-fiber, low fat diet that is recommended for everyone else. (*Refer to the National MS Society publication “Food for Thought: MS and Nutrition” for more detailed information*).

As is true for the rest of the population, the most common causes of death in people with MS are heart disease and cancer. A high-fiber, low fat diet has been shown to promote cardiac health and reduce the risk of certain types of cancer for all adults. This type of diet also helps to promote weight control which, in turn, enhances mobility and reduces fatigue. People with MS are at increased risk for osteoporosis (thinning of the bones) because of reduced mobility and increased use of steroids. Therefore, it is also important for your dietary regimen to contain sufficient amounts of calcium, as well as the magnesium and vitamin D your body needs to utilize calcium effectively.
Meeting your emotional & spiritual needs

Health and wellness are not just physiological; emotional and spiritual needs are important as well. Each person’s needs are different, and each of us must work to develop a support system that meets those needs. Family members and friends are a common source of support and strength. Prayer or other spiritual connections can be helpful as well. Many people have discovered a personal support system on the Internet, sharing their feelings and concerns with others online. Still others find support and solace from their pets.

The National MS Society offers a variety of support programs, including educational activities and self-help groups, for you and your family. The Society can also refer you to mental health professionals with expertise in the area of chronic illness, who are familiar with the stresses and challenges of living with a disease like MS.

It doesn’t matter what constitutes your system of support — the important thing is that you have one. Your emotional wellness will thrive on the support you derive from having someone who cares and listens to you on the days you feel alone and frustrated with your life, the world or your changing body.

Another component of emotional wellness is the ability to manage the many kinds of stresses that are inherent in our daily lives. The relationship between stress and the onset and progression of MS is not at all clear. While many people with MS feel certain that stress caused their disease or contributes to its progression, research has not been able to identify any definite link between MS and life stress. What is certain is that stress is an unavoidable part of everyday life, and efforts to avoid stress completely (e.g., by leaving one’s job or curtailing important life activities) inevitably lead to frustration and more stress.

The most helpful strategy seems to be to develop techniques to manage the stresses that bombard us. The first step is to identify the major sources of daily stress. The second step is to explore a variety of stress management techniques and identify the ones that feel most effective. Let’s look at these one at a time.
EXERCISE H

Using a stress log to identify common stresses in your life

Over the next week or two, use the Stress Log in Appendix B (pp.30–32) or a voice recorder to record your most stressful events. Keep in mind that stress can result from both negative and positive events in your life. For example, you can be as stressed by the prospect of a long trip or preparing for a houseful of company as you can be by a bad day at work or a fight with your spouse. A stressful event can be anything that makes you feel pressured, anxious or generally distressed.

Review the events in your log and try to look for any patterns in the ways you tend to respond to the stresses in your life. Are there any patterns you would like to change? For each item on your list, think about how you might respond to it in a different or less stressful way. The next time a similar event arises in your day, try experimenting with this alternative response. Did your new ways of responding result in less stress for you? Have you learned anything from implementing these new responses?

If most of your daily stresses seem to come from too many things to do and not enough time and energy to do them, you might want to take a fresh look at your priorities. Many of us try to hold on to all the things we always thought we had to do before MS entered our lives. Our list of “must-do’s” can become one of life’s major burdens.
EXERCISE I

Identifying your priorities

Answer the following questions:

1. How many of the stressful events in your daily life involve things that you really want to be doing?

_____________________________________________________________________________

2. How many involve things you think people expect you to do?

_____________________________________________________________________________

3. Are you a person who has trouble saying the word “no” (to yourself or others)?

☐ Yes  ☐ No

4. If you had enough energy to accomplish just three things each day in addition to your basic activities of daily living (washing, dressing, eating, etc.), what would they be?

_____________________________________________________________________________

_____________________________________________________________________________

_____________________________________________________________________________

5. Are there things you want to do for your own satisfaction, or things you think someone else expects you to do?

_____________________________________________________________________________

*If they are someone else’s selections, it is probably time to re-examine your choices.*
This is not to suggest that you should stop doing things for your family, give up the career that you have managed to develop or curtail the volunteer work that makes you feel worthy. If you have chosen these activities as most valuable to you, then they should be at the top of your list. Talk to those close to you about your needs and about what is currently stressful for you. Make sure you’re not doing things for others that they would be happy to do themselves, especially if their participation would allow them to have quality time with a less-stressed you.

In spite of all your best efforts to examine your priorities and reduce your daily stresses, life will continue to present many unavoidable hurdles. The key to living more comfortably with these stresses is to explore various stress management techniques and find the ones that work best for you. You might benefit from talking with friends, taking a class in yoga or Tai Chi, keeping a diary or listening to music. Or you may find that prayer or meditation, pursuing a hobby or taking a walk might be more helpful. There is no single technique that is right for everyone.

If you are having trouble finding a stress management strategy that works for you, or if you feel that your stresses have become too overwhelming to handle on your own, don’t hesitate to make use of the resources available to you. The Society can refer you to a mental health professional in the area who can help you learn to manage the stresses in your life. There is no need for you to feel that you have to do this all on your own.
EXERCISE J

Rallying your support system

Fill in the blanks:

1. When I feel particularly down, it helps to:

_____________________________________________________________________________
_____________________________________________________________________________
_____________________________________________________________________________

2. I feel comfortable asking the following people for help:
   a. __________________________________________________________________________
   b. __________________________________________________________________________
   c. __________________________________________________________________________
   d. __________________________________________________________________________

3. I feel better when I:

_____________________________________________________________________________
_____________________________________________________________________________
_____________________________________________________________________________
CONCLUSION

Wellness is a goal we can all work to achieve, regardless of our level of disability. This workbook is designed to help you define wellness for yourself, and find ways to live well with MS. Keep in mind that wellness cannot be achieved in a week or a month; it is really the process of a lifetime. The first step is to identify one or two long-range goals that you would like to achieve over the next year. Then, to help you get started, try to identify two or three short-term objectives that will help you achieve each of your long-term goals. Remember that there are a variety of resources available to help you; your healthcare providers can work with you to assess your health and wellness needs. The National MS Society can steer you toward valuable programs and resources in your area; this workbook can serve as a guide along the way. By reviewing the exercises once or twice a year, you will be able to chart your progress toward the goals you have set, and identify new goals towards which you want to strive. Good luck with your efforts — and be well.
APPENDIX A

Energy diary

Instructions & sample energy diary

1. At each time during the day, place an X to indicate whether your energy level is very high (maximum), very low (minimum) or somewhere in between.

2. Indicate a rest period (without sleep) by placing an R in the appropriate time period.

3. Indicate a nap (sleep) by placing an N in the appropriate time period.

4. At the end of the week, draw a line connecting all of the X marks for a given day. Compare the energy lines for all of the seven days to see if your energy pattern is consistent across days, or if it varies from one day to the next. Look to see if rests or naps enhance your energy level.

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<thead>
<tr>
<th>Time</th>
<th>7:00AM</th>
<th>9:00AM</th>
<th>11:00AM</th>
<th>1:00PM</th>
<th>3:00PM</th>
<th>5:00PM</th>
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| MAX      |        |        |         |        |        |        |        |        |         |
| Monday   | X      | X      | X       | N      | X      | X      | X      | X      | X       |
| MIN      |        |        |         |        |        |        |        |        |         |

| MAX      |        |        |         |        |        |        |        |        |         |
| Tuesday  | X      | X      | X       | R      | X      | X      | X      | X      | X       |
| MIN      |        |        |         |        |        |        |        |        |         |
## Your energy diary

<table>
<thead>
<tr>
<th>Time</th>
<th>Sunday (MAX)</th>
<th>Sunday (MIN)</th>
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<th>Monday (MIN)</th>
<th>Tuesday (MAX)</th>
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<th>Friday (MAX)</th>
<th>Friday (MIN)</th>
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Stress log

Instructions & sample stress log

1. For each day of the week, identify one or two stressful events. In the first column, briefly describe the event that took place. Then, make a note of the thoughts and feelings you were having as the event took place. In the third column, describe how you handled the situation. In the last column, list other possible ways you could have dealt with the situation.

2. Using this template, complete the exercise for an additional week or two. At the end of each week, review your stressful events to see if there are any patterns or consistencies in a) the types of events you find most stressful, and b) the ways you tend to handle these types of stresses.

3. Experiment with your alternative strategies to see if they help reduce the stress in these situations.
## Sample stress log

<table>
<thead>
<tr>
<th>DATE</th>
<th>WHAT HAPPENED?</th>
<th>WHAT DID I THINK?</th>
<th>HOW DID I FEEL?</th>
<th>WHAT DID I DO?</th>
<th>WHAT WILL I TRY NEXT TIME?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sunday</td>
<td>Argument with my spouse</td>
<td>“He never understand.”</td>
<td>Upset</td>
<td>Went to sleep</td>
<td>Explain my feelings</td>
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<tr>
<td></td>
<td>Friends dropped over</td>
<td>“I can’t handle this.”</td>
<td>Tired and overwhelmed</td>
<td>Pushed myself to cook dinner</td>
<td>Order in pizza</td>
</tr>
<tr>
<td>Monday</td>
<td>Parent-Teacher Conference</td>
<td>“Why isn’t this school accessible?!?”</td>
<td>Angry and sad</td>
<td>Spouse went without me</td>
<td>Ask school for Accommodation</td>
</tr>
</tbody>
</table>
### Your stress log

<table>
<thead>
<tr>
<th>Date</th>
<th>What happened?</th>
<th>What did I think?</th>
<th>How did I feel?</th>
<th>What did I do?</th>
<th>What will I try next time?</th>
</tr>
</thead>
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<td>Sunday</td>
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<td>Saturday</td>
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</table>
SUGGESTED READINGS & RESOURCES

Books


DVDs

Armchair Fitness

armchairfitness.com
(800) 453-6280

Yoga For MS

Demos Health
demoshealth.com

Yogability and You with Shelley Sidelman

yogabilityandyou.com

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

General Information:
Choosing the Right Healthcare Provider

Staying Well:
Exercise as Part of Everyday Life
Food for Thought: MS & Nutrition
Intimacy & Sexuality in MS
Multiple Sclerosis & Your Emotions
Preventative Care Recommendations for Adults with MS

Stretching for People with MS

Stretching with a Helper for People with MS

Vitamins, Minerals, & Herbs in MS: An Introduction

Managing Specific Issues:

Fatigue: What You Should Know

Living with MS

MS & the Mind

Pain: The Basic Facts

Sleep Disorders & MS: The Basic Facts

Solving Cognitive Problems

Taming Stress in Multiple Sclerosis

Urinary Dysfunction & MS

Online

Can Do Multiple Sclerosis Webinars

mscando.org

Fatigue: Take Control

nationalMSsociety.org/fatiguevideo

Hold That Thought: Cognition & MS

nationalMSsociety.org/cognitionvideo
Live Fully Live Well

nationalMSsociety.org/LiveFullyLiveWell

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

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)