Fighting Fatigue in Multiple Sclerosis

Practical Ways to Create New Habits and Increase Your Energy

Nancy A. Lowenstein
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Nancy Lowenstein, OTR
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FOREWORD

Fatigue is a major problem in multiple sclerosis, affecting as many as 90% of individuals with the disease. It is most commonly defined as a sense of exhaustion and is often solely attributed to just mood or impaired physical functioning. Yet, fatigue is a symptom in its own right. Pharmacologic management is usually quite incomplete in solving the problem and non-pharmacologic interventions are critically important. When fatigue is not addressed it can lead to tremendous frustration and adversely affects quality of life for the person with multiple sclerosis, the family and health care provider.

In this wonderfully practical and highly individualized approach to fatigue, a very important management strategy is laid out in a detailed manner. Such an approach is critical for a symptom which causes such diverse problems. The specific recommended guidelines can lead to a dramatic improvement but will require individuals to be highly motivated and conscientious. Fortunately, the vast majority of individuals with multiple sclerosis have just this type of motivation and wish to improve their lives and reach their maximum potential. As outlined in this book, the key is to control the disease rather than be controlled by it. Fatigue can be effectively treated and this guide can provide the way. The step by step approach addresses fatigue head on and provides the necessary tools to overcome this pervasive symptom.

Lauren B. Krupp, MD

Professor of Neurology and Psychology at the State University of New York at Stony Brook and Medical Center, co-director of the adult MS Center at Stony Brook, and author of Fatigue in Multiple Sclerosis: A Guide to Diagnosis and Management
Preface

This book came about due to my 10 years working at the Mount Auburn Hospital Comprehensive Multiple Sclerosis Care Center where I have taught energy conservation techniques to people living with multiple sclerosis. I have done many presentations and workshops for the New England Chapter of the National Multiple Sclerosis Society on fatigue management. Learning to manage fatigue requires changes in the way you think about yourself, changes in the way you do tasks, changes in your routines and habits, and involves help from your family and friends.

This book will work best if you read the chapters in order and if you do the exercises and activities throughout. There is no magic pill for managing fatigue, and this book does not suggest that you stop taking medication that your doctor has prescribed. However by learning the techniques in this book, in addition to any medication you are taking, you should begin to feel more in control of your life and your symptoms of fatigue.

Additionally, managing your fatigue should not be something you try and do alone. By involving loved ones, friends, co-workers and health care professionals, you will have a greater chance of being successful. It may seem that you are “giving in” to your multiple sclerosis if you ask someone else to cook dinner, or drive the kids to activities, however, if you are then able to enjoy more quality evening time helping with homework or reading at bedtime, isn’t the payoff worth asking for the help?
You will need to take an honest look at your priorities, to not attach who you are to what you can or cannot do. It is also important to understand that change takes time and patience. Be kind to yourself, applaud your successes and don’t get down on yourself if you can’t stick to your new behaviors 100% of the time. It takes around 6 months to develop a new habit. Learn to laugh at your mistakes, tell others what you are trying to do so they can help you.

If you are feeling the need for more formal support and instruction, there are professionals who are available as well. An occupational therapist can teach you many of the energy management techniques in this book. They can also look at your environments and make suggestions for ways to make these work better, they can also show you adaptive equipment that might be useful. A physical therapist can help you develop an exercise routine and talk to you about external supports for walking, such as a cane, walker, or scooter. A psychologist or social worker can help you with anxiety or depression, two conditions that may impact how tired you feel. In addition there are professionals who can help you with clutter, housekeeping, exercise and even doing errands.

I hope that this book provides you with ideas to help you feel more empowered and better able to manage your fatigue. The techniques in this book may also be helpful for those without multiple sclerosis. If you know others who are trying to fit everything in to busy lives, teach them the techniques that you learn throughout this book.

_Nancy Lowenstein, MS, CTR, BCPR_
ACKNOWLEDGMENTS

I want to thank all the individuals with multiple sclerosis who have taught me so much over the years about how MS affects them on a daily basis. Also my colleagues at the Mount Auburn Hospital Comprehensive Multiple Sclerosis Care Center for their support of this project, especially Ann Pisani, RPT for her help with the chapter on exercise. Last, but not least all my occupational therapy students who volunteered to assist with this project, some who wrote whole chapters and others, like Allyson Marvin, who provided outlines.
FIGHTING FATIGUE IN MULTIPLE SCLEROSIS
Conserving your energy was probably not something you thought about before you were diagnosed with multiple sclerosis. You were able to go through your day without worrying about when you were going to “hit the wall.” You managed all aspects of your life, from personal needs to family demands to work and leisure time. Now, however, you find yourself losing energy by midmorning or later. The tank gets empty much quicker and is harder to refill. By the end of the day, you are wondering, “What did I do today that made me so tired?” This chapter will help you to realize that your daily life is very energy consuming, even if you don’t think so. Throughout this book, you will learn about your daily
activities and which ones take a lot of your energy and which ones help to restore your energy.

In this chapter you will learn

• The importance of habits and routines
• Where your energy may be leaking out
• How emotions and stress impact your energy levels

Night Owl or Lark?

Our energy levels naturally ebb and flow in cycles throughout the day. These are called circadian rhythms. We each have our own patterns and preferences: some of us are “morning” people; others are “night owls.” Some people jump right out of bed, ready to attack the day, and others take awhile to hit their stride. Take the quiz, “Are You a Night Owl?” to see if you are a night owl, a morning person, or an intermediate.

Maybe you are a night owl who has learned to live in a morning world. You may still have these natural patterns and, with multiple sclerosis, your old patterns may be taking over again. Learning about your daily patterns and how to manage your day in accordance with your natural energy cycles is an important aspect of managing fatigue.

Why am I so tired if I haven’t done anything yet?

For as long as you can remember, you’ve performed many daily tasks. It’s gotten to the point that, now, you don’t even think about them anymore. These are called habits and routines. Habits are those activities that you do automatically,
Are you a Night Owl?

Think about a time before you had multiple sclerosis when answering these questions.

In the morning,

1. I don’t usually rely on an alarm clock or I wake and get out of bed as soon as the alarm rings.
2. I hit the snooze button. I hit the snooze button. I hit the snooze button. Eventually, I drag myself out of bed.

At 9:30 in the evening,

1. I have been in bed for an hour.
2. I am doing the laundry, vacuuming, and baking bread.

The time of day that I am most alert and energetic is

1. Early morning.
2. Afternoon.
3. Late evening.

If you answered 2, 2, 3, you are a night owl; if you answered 1, 1, 1, you are an early bird. An intermediate person may respond to some questions as a night owl and to others as an early bird; intermediates are often able to be more flexible with their schedules. This information was originally published in Birds of a Different Feather by Carolyn Schur and is used with permission of the author and Schur-Goode Associates.
without thinking. When performing habits, you can multi-
task. For example, you can usually get dressed while talk-
ing on the phone or checking email, without forgetting
what you’re doing (except if you have cognitive prob-
lems—problems with thinking or memory). When you get
into your own car, you don’t think about where your key
goes; you simply put the key in the ignition. Routines are
a series of tasks, such as a child’s bedtime routine or a
morning routine, which may consist of showering, dress-
ing, and getting coffee.

The habits and routines that you have performed with-
out thinking for so many years can now seem exhausting,
and you may wonder why. For one thing, many of these
activities consume high levels of energy. Showering is akin
to aerobic activity. In the shower, you stand, bend, reach,
and move your arms and legs nonstop for 15 to 20 minutes.
Then, you get out of the shower and dry yourself, which
involves more standing, bending, and reaching. Then, you
get dressed, during which you stand, bend, and reach
some more. Finally, you make breakfast, which involves
even more standing, bending, and reaching! Of course
you’re tired—you just had an aerobic workout! If you have
balance problems, spasticity, or pain, you have been work-
ing even harder—expending even more energy. And this
is only your morning routine. What if you are a parent car-
ing for young children who need you to bathe, dress, and
feed them, or what if you need to drive 40 minutes in
stressful rush-hour traffic?

I think by now you get the point that your daily activ-
ities involve a lot more than you may realize and that,
when you string together a series of routines, you may
simply be burning through all of your energy and all of
your reserves.
To understand how you spend your time and where your energy might be going, it may be helpful for you to list the routines and habits that you engage in on a regular basis. Use Chart 1 to list your routines and then list the “habits” or activities that make up each routine.

I don’t want to give in to my multiple sclerosis, so I need to walk a lot

Multiple sclerosis causes multiple physical symptoms—muscle weakness, spasticity, difficulty walking, tremors, ataxia, and pain, to mention a few. If you have any of these symptoms, you’ll need to expend more effort to move correctly or to maintain proper posture. Fighting these physical symptoms by walking without the support of assistive devices, such as a cane, rollator, walker, or leg orthotics, is a huge source of lost energy. Your body is working extra hard to move correctly, and you will fatigue more quickly just by trying to compensate for your physical issues. It is important to consider these issues as you look at managing your fatigue. Perhaps you’ll want to use a device to help you manage your physical symptoms, in the same way that you may be taking medications to manage other symptoms. In Chart 2, list your physical symptoms, how they affect you, and what you might be able to do about them.

I sit at a desk all day, why do I feel tired?

You’ve now looked at your routines, habits, and physical symptoms, but other activities that you may not have considered may be causing your fatigue. We all know that being physically active can make us tired, but using “cognitive”
# Chart 1

**Habits and activities that make up my daily routine**

<table>
<thead>
<tr>
<th>Routine</th>
<th>Habits/activities</th>
</tr>
</thead>
<tbody>
<tr>
<td>Morning routine (example)</td>
<td>Shower</td>
</tr>
<tr>
<td></td>
<td>Groom (make-up, shave, dry/style hair)</td>
</tr>
<tr>
<td></td>
<td>Dress</td>
</tr>
<tr>
<td></td>
<td>Make a light breakfast</td>
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</tbody>
</table>

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NANCY LOWENSTEIN, OTR
# Chart 2

**Physical symptoms: How they affect me and what I can do about them**

<table>
<thead>
<tr>
<th>Physical symptoms</th>
<th>How it affects me</th>
<th>What I can do about it</th>
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energy, that is using our minds, can result in fatigue as well.

Reflect on a time when you had to sit in a class, meeting, or other venue in which you were listening and thinking more than you were moving around. Were you tired at certain times? Did you look at your watch to see when the event would be over? Did you leave at the end of the class or meeting feeling exhausted? Just like your body, your mind requires energy to run. Being in a meeting or classroom requires you to sit still but upright, to process what many people are saying, and to remain focused on multiple sources of input, perhaps a document, a presentation, and a speaker all at once. Even if you don’t have any cognitive impairment, your mind must work very hard to manage all of these inputs. If you do have cognitive impairments, you will use even more cognitive energy in these situations. Take some time to think about all of the cognitive tasks that you complete on a daily basis—these include cognitive tasks both at work and at home—and write down your tasks in Chart 3.

Have you ever noticed that you feel tired even after doing an activity while sitting down, such as crafts, computer work, or even preparing a meal? Why is sitting down and not doing anything physical so tiring? The answer lies in the mechanics of muscles: when you are sitting, you are asking your trunk muscles to support your body in an upright fixed position for long periods of time; your arms are being held in a fixed, and perhaps, unsupported position (see ergonomics in Chapter 7); and your head is also being held in a flexed forward and fixed position. These fixed positions require your muscles to hold contractions for long periods of time to keep you in the positions, and, by not moving around, you are not increasing your blood
Chart 3
Cognitive tasks that I regularly do at home and at work

I regularly do the following cognitive tasks

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

9

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flow. Additionally, your eyes are working very hard to remain focused on the task. Include the mental activity of attending to the task, and it all adds up to very large energy consumption. This holds true whether you are doing the task for leisure, fun, or work.

Reflect on the amount of time that you spend each day on tasks while you are seated. You can use the examples in Chart 4 to get started.

**Chart 4**

*Time spent on various sedentary activities*

I sit in one place for ____ minutes at a time when doing a task.

I look at the computer screen for ____ minutes without a break.

I sit in or drive a car for ____ minutes without a stretch break.

**Emotional energy**

Our emotions also eat up valuable energy. Anger, depression, and stress all require large amounts of “emotional” energy. A variety of biologic processes take place when your emotions are high. During stressful times, your body produces chemicals to help you cope with the situation. These substances increase blood flow, reaction time, and the rate of other biologic process. When the stressor is removed, your body goes into a relaxed state again, leaving you more tired than before you were stressed. Long-
term stress can have an impact on your health and immune system as well, so it is important to be realistic when looking at your own stress levels and to seek help from an appropriate professional. It is not possible to avoid everyday tensions, but it is important to recognize the role that stress plays in fatigue and to learn how to manage stress. Think about areas in which you expend emotional energy, and jot your thoughts down in Chart 5.

Chapter Summary

In this chapter, you learned that your daily energy is finite and that there are many ways that the steam seeps out of you throughout the day. You may not even be conscious of the many ways that you lose energy. Your daily routines and habits, your cognitive tasks, and your emotions all require energy. Whether you are a day or night person will be an important factor when it comes to figuring out how to create a more efficient routine. This book will help you to explore all of these areas and to learn skills that may help prevent your strength from “leaking” out during the day.

In the next chapter, you will take a look at how your days are structured and examine how this structure may be having an impact on your fatigue levels.

Reference

Chart 5
How I expend emotional energy

<table>
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<tr>
<th>Things that regularly stress me</th>
<th>I get angry easily when</th>
<th>I feel depressed and sad about</th>
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