

CHAPTER 2

Getting Things Done: Managing Your Time and Energy

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YOUR PERSONAL CHALLENGE

Getting things done involves work. In this chapter, we define *work* in its broadest sense, as an activity that you perform to accomplish something. Your “life’s work” can range from taking care of yourself, to cooking a meal for your family, to being a board member of a charitable organization. Work includes doing all of the things in your life that are necessary for survival or have value for you. When you are living with multiple sclerosis (MS), work is often done in the presence of obstacles that may make accomplishing the work difficult.

In this chapter, we outline not only the barriers you may face to participate fully in work, we also describe some ways to deal with these barriers. Finally, we provide suggestions for sources of help to aid you in pursuing the work you wish to accomplish.

BARRIERS TO FULL PARTICIPATION

Before discussing strategies for dealing with difficulties in getting things done, we need to understand the three major difficulties: fatigue, changes in thinking, and stress. Each of these may be a major challenge for you and, in combination, they may create a cycle so vicious that it makes matters even worse. We begin with a description of each barrier and then we will describe how they combine to form a cycle of difficulty that may be greater than the sum of its parts.

FATIGUE

Fatigue is the feeling of lacking the physical and/or mental energy to do the activities you wish to accomplish. If you have MS, fatigue is very common. Almost 80 percent of people with MS experience some level of fatigue and it is the most commonly reported symptom (MacAllister and Krupp 2005). Fatigue is described as being the “worst” symptom by about one-third of those who have MS (Krupp et al. 1988). Fatigue can have a profound influence on your life. What you do, how much you do, and when you can do it can all be disrupted by fatigue. One woman with MS put it simply. She said, “Fatigue dictates my life.” The fatigue associated with MS is different from the types of fatigue other people experience (National Multiple Sclerosis Society 2003). Although it may be unpredictable from day to day, it generally occurs on a daily basis and tends to worsen as the day progresses. It is often aggravated by heat and humidity. Finally, fatigue is a challenge because it is invisible to others and may be misinterpreted as depression, a lack of effort, or as just not trying hard enough.

CHANGES IN THINKING

Changes in thinking or memory are also common, occurring in about half of people with MS (LaRocca and Kalb 2005). Like many aspects of MS, changes in thinking vary considerably from person to person due, at least in part, to the location, number, and activity of MS lesions. There is general agreement that changes in thinking are not global; that is, they do not affect all of the functions of the brain but rather target specific processes such as memory and information processing. These changes in thinking can make it difficult for you to do more than one thing at a time or to perform complex tasks when there are time pressures.

At times, fatigue and changes in thinking are difficult to separate from each other. Fatigue can be described in many ways, including weakness, lack of stamina, feeling “spacey,” having poor concentration, feeling bored, or just general dissatisfaction. It is important to appreciate the mental aspects of fatigue because often they make thinking clearly more difficult. One man with MS described the mental aspects of fatigue this way: “Fatigue is the cognitive mud that I have to slog through before I can think clearly.”

STRESS

Stress is the third in this series of challenges often faced by people with MS. *Stress* can be described as a feeling or sense of uneasiness. It is an internal feeling associated with being anxious or feeling overwhelmed. Situations that previously would not have been stressful for you may become a problem because of diminished capacity for thinking clearly and fatigue. Feeling anxious can be exaggerated by fatigue, changes in thinking, and demanding tasks. You might view stress as clearly undesirable because it is associated with a worsening of symptoms. There are resources available for achieving more stress-free productivity (see Allen 2001).

It may be helpful for you to consider stress when you evaluate or judge a specific situation and not the situation itself. In other words, any given situation may be viewed as stressful by one person and enjoyable by another. For example, the necessity to juggle many things to do your work may be viewed as either “adding spice to life” or as overwhelming and stressful.

Once you may have thrived on stress related to various activities, but now you may find stress interfering with getting things done. You may become anxious with complex tasks and fearful of failure. The stress may be unpleasant and even emotionally overwhelming. Clearly, cognitive changes and fatigue will influence your evaluation of situations as either stressful or not.

The Vicious Cycle

Fatigue, changes in thinking, and stress can encircle those with MS as shown in figure 2.1. For example, fatigue may bring about difficulty in thinking. The cycle continues, because thinking requires effort and attention and that, in turn, results in more fatigue. A woman with MS described the cycle of changes in thinking and stress this way: “It’s kind of like a revolving circle effect, the more stress there is, the more confused I get, and the more confused I get, the more that stresses me.” This cycle creates a formidable barrier to getting things done because fatigue, cognitive change, and stress are variable, somewhat unpredictable, and invisible to others. Furthermore, the cycle can be worsened by a variety of external factors like trying to do too much, trying to do too many things at once, demanding situations, or demanding people.

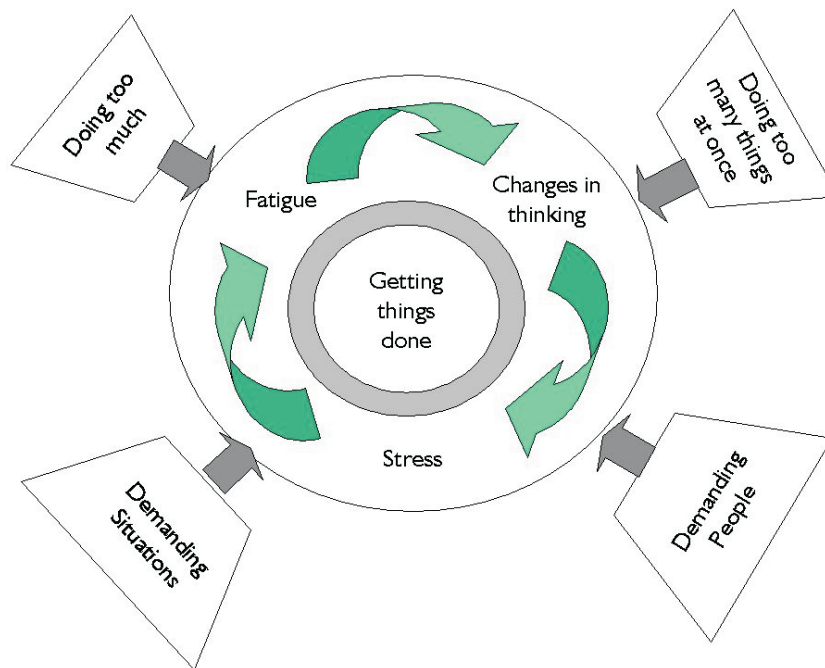


Figure 2.1: The vicious cycle that may interfere with getting things done.

In managing your time and energy, you need to find the right balance in the costs and benefits of getting work done. Your balance can be upset by several factors, including change in the symptoms of MS, daily variability in energy and cognition levels, as well as stressors and other barriers in the environment. Maintaining your balance may require you to initiate and develop a series of strategies with the resources available to you. In the next section, people with MS describe how constructing their sets of strategies enables them to participate fully in life.

DEVELOP YOUR OWN STRATEGIES TO DEAL WITH MS

Many factors make each person with MS unique. These include the set of symptoms that you experience, how these symptoms vary from day to day and over time, the activities you value, and your daily life situations. Although healthcare providers and family members may be well-informed, only you—the person with MS—can truly know about your own experiences. For that reason, only you can decide on the best strategies for yourself.

Over the past five years, we've talked with many people who have MS about what it's like to live with this condition (Johnson et al. 2004; Yorkston et al. 2003). We call the approach to developing strategies these people told us about by the acronym PACE. This provides an easy way to remember the four most important steps: **P**riorities, **A**wareness, **C**onstructing your strategies, and **E**valuation. The following section provides a step-by-step exercise to help you develop strategies that will work for you.

Priorities

Let's begin with priorities. A *priority* is something you give attention to or focus on before anything else that may be competing for your time or attention. It is what you value. Many people described how MS required them to establish a new set of priorities, a new way of looking at the things they did every day. They described how essential it is to devote time and energy to the important things that you value while reducing your concerns about less valued activities. Given limited energy and resources, it is important for you to define what is important to you, to set priorities. One of the people we interviewed put it this way:

You learn that life is short and you quit worrying about stuff that doesn't matter. You only have so much energy and don't have the energy to fuss and fiddle with things that are not going to matter in the long run. So you learn to focus on what's important.

Note that priorities differ from person to person. For you, continuing a cherished job may be a priority; for others, child-rearing comes first. If your symptoms worsen, your priorities may change. You need to get in touch with what you value most. Many people with MS expressed the idea that they need to be in charge of developing their own plans. Having the sense of control over your life decisions is very important.

Now it's time for you to figure out what your priorities are. It's important to figure this out so you will know on which parts of your life you want to focus your limited energy and time.

Worksheet 3 lists the five domains that most people feel are important to them. The first domain is called Taking Care of Yourself. This might include a variety of activities you choose to promote for your physical, psychological, or spiritual well-being. Getting adequate exercise, enough rest, and good nutrition might belong to this domain along with other matters like reducing your feelings of stress.

The second domain is Family and Household. This might include your priorities related to the management of your household and the people who live in it. The third domain is Leisure or Discretionary Activities that you enjoy. The fourth is your Career. This may involve paid or unpaid employment or schooling. The final domain is Taking Part in Your Community and it may involve priorities that relate, for example, to the roles you choose to play in your community organizations.

Instructions for Worksheet 3

Try to list two activities you believe are your priorities in each domain. Priorities must be specific, otherwise they will seem unachievable. For example, the priority to “get a good job” is too vague and needs to be more specific. What does “good” mean to you? Does it mean flexible hours, a brief commute, great benefits, or friendly coworkers? Carefully defining your priorities increases the likelihood that you will be able to accomplish them. Then, having met your priorities, you can set new ones. It’s okay to start with general priorities so long as you define your terms to make the priority specific, for example, what do you mean by “good” in the priority “getting a good job.”

After you’ve listed your two priorities for each domain, pick the one that is most important to you in each domain. After you do this, pick the domain and its top priority that you want to work on first. It is important to not allow yourself to be overwhelmed by trying to work on too many priorities at once.

WORKSHEET 3: PRIORITIES

Taking care of yourself: _____

Family and household: _____

Leisure or discretionary activities: _____

Career: _____

Taking part in your community: _____

Awareness

After you’ve thought about your priorities, you need to become aware of potential barriers to getting things done and the resources you have to get around those barriers. The people we interviewed described a number of factors (or triggers) that caused them to change how they did things. Sometimes the factors were internal and associated with the symptoms of MS, for example, fatigue or changes in thinking. Other factors were associated with the environment and the stresses present in certain situations. For example, a first-grade teacher described how the classroom situation was stressful to her because it required her to

pay attention to so many things at one time. She said about her job: “I think it’s just overload in a job like this when you must deal with twenty-five first graders and the demands of the day, that sometimes little things would get lost or that you would become forgetful.”

Certain internal symptoms or environmental triggers will signal to you that change is needed. The people we interviewed also described the need for vigilance or awareness of the factors that signal the need to change how they handled their affairs. They appeared to monitor their potential triggers very carefully. For example, one woman said, “You have to listen to your body because if you don’t listen to your body, you are absolutely going against the current.” Another woman had developed a daily self-monitoring routine by doing a crossword puzzle in order to “take inventory.” She described it like this:

The crossword puzzle gives me three kinds of information. One, how’s the fine motor control? Are my tremors bad today? Two, how’s my cognition? Can I find the words that I’m after? And three, how’s my strength and endurance? Do I have the energy to finish the puzzle today?

The degree of awareness you cultivate will give you information about how things are going; it involves being alert for and anticipating potential problems. For you to function at your best, you need to stay vigilant to the clues that changes are needed.

To achieve your priority goals, or to accomplish anything, you must learn about the resources available to you when you need to get the work done. For example, one woman described how she was always “looking for solutions.” She had the time and energy to maintain her job outside the home, but only if she hires someone else to clean her house. In addition to providing her with the satisfaction of her work and with social contacts, keeping her job gave her the financial resources to hire the help she needed to maintain her household.

Finding solutions means selecting from the resources available to you. If your resources are limited, you may need to be creative. For example, can a high school or college student clean your house, run errands, shop, or do the other chores that you find difficult or tedious? If you have little money, you might barter to get the help you need (do some computer work for someone, provide a free room in your house, etc.). You can identify what you have to offer to get the critical help that you need.

Now let’s continue the work you started when you listed your priorities. In worksheet 4, write down the specific priority that you’ve selected as your first goal. Then think about barriers that prevent you from accomplishing that goal and write them down. Finally, think about the resources you have that may help you to get around those barriers. Remember to be creative and get help in identifying your resources if that seems necessary.

WORKSHEET 4: AWARENESS AND CONSTRUCTION OF STRATEGIES

What Priority Are You Working On? _____

Barriers to getting it done: _____

Resources you have: _____

Strategies you might use: _____

Constructing Your Strategies

Many people we interviewed described a process where they began doing things in different ways. One man said, “MS doesn’t really affect what I do. Rather, it affects how I do it.” Changing how things get done involves constructing and employing a personal set of strategies. This is a process of combining elements in order to accomplish a specific task. In other words, use your strengths and resources to do things. Table 2.1 below shows examples of a number of strategies developed by people with MS along with the factors that triggered their use of these strategies. For example, one woman said that she always takes extensive notes during business meetings because she becomes easily fatigued at long meetings. She commented, “I usually write a lot of notes so that a little bit later, when I have more energy and I’m able to think more clearly, I can review them. Writing things down also helps me think more clearly too.”

| Table 2.1: A Description of Selected Strategies | | |
|---|--|--|
| The Strategy | Benefit of the Strategy | Cost of the Strategy |
| Take notes during business meetings | Increased attention during meetings and good review of ideas afterward when energy level is higher | Don’t participate as actively in the meetings |
| Begin work at 5 A.M. and leave by early afternoon | Important work done without distractions and when not fatigued | Need to negotiate with supervisors about my work schedule |
| Midday rest breaks at work in private quiet room | Reduced fatigue and increased concentration | Social isolation from fellow employees during break time |
| Household organization, e.g., cleaning products always in appropriate locations | Reduced energy expended in finding and gathering supplies before doing household tasks | Others in household must help maintain organization |
| Desk and parking place reassignment to minimize walking distances | Decreased fatigue | Need to negotiate with employer |
| Desk clear except for appropriate paperwork | Can concentrate on one thing at a time | Time spent in shifting materials for each task |
| Making a daily to-do list | Priority tasks were accomplished, reduced the stress of trying to remember everything | Time to construct the listings; appreciating how many things could not be accomplished |

Here's an example of a strategy used to compensate for cognitive changes. One woman keeps her desk at work "really neat" with only the papers relating to the task at hand on her desktop. She reported that this prevented her from "getting sidetracked."

Other strategies involve organizational techniques for completing household work. One person we talked to kept a very orderly home. She spoke about her need for order:

I can't be scattered. Things have to have a place. If I want to go get the furniture polish for cleaning my woodwork, I have to know it's there. I don't want to walk to the hall closet and then discover that it's just not there. That wastes too much energy!

Now let's continue the work you started earlier. Go back to the priority you chose to work on. In worksheet 4, you listed some barriers and also some resources to get around those barriers. Now, we would like you to brainstorm some ways that might help you to accomplish your priorities. While you are doing this, keep two things in mind. First, there are no "wrong" answers. Just come up with anything you can think of as a way to achieve your goal and write it down. Second, keep your barriers and resources in mind and while you are strategizing, think of ways that these barriers may be overcome. If you get stuck, ask for help from a resourceful friend or your significant other.

Evaluating Your Strategies

The last important step to take when developing strategies is for you to evaluate them. Periodically, people with MS need to ask themselves this question: Does this strategy still work for me? You can evaluate your strategies by weighing their costs and benefits (as in table 2.1). For example, an elementary school teacher needs to take rest breaks during her teaching day. She uses a quiet room away from the other teachers' break room where she can relax in a recliner. Although this rest break is both beneficial and necessary, she knows it also has a cost; she commented, "It is rather isolating as well as good for my health."

In this particular case, the benefits outweigh the cost and she continues the practice. For some people, however, the value of their strategies may change over time. Some strategies may be very effective in some situations but less so in others. For these reasons, your evaluation process is important when making decisions about when, where, and with whom to use your strategies.

Once you've employed some of the strategies you thought up, it's essential that you go back and do a final review. This will give you the opportunity to see what helped and what didn't work, and to try out other strategies that might work better.

Use worksheet 5, below, to list the benefits and costs of a strategy you are using. After doing the work, and thinking about this, rate both the benefits and costs of the strategy. These ratings will help you decide whether to continue using these strategies or if you need to modify them.

If a strategy doesn't work for you, go back and try another. Brainstorming with some other people may be a good way to figure out how to make certain strategies work better for you or how to create new ones.

WORKSHEET 5: EVALUATING YOUR STRATEGIES

What is your strategy? _____

List some ways that it is helpful: _____

Check the appropriate box to determine how helpful this strategy is:

| | Very helpful | Helpful | Helps some | Neutral | Not helpful |
|-------------------|--------------|---------|------------|---------|-------------|
| This strategy is: | | | | | |

Now, list some of the costs of using this strategy: _____

Check the appropriate box to determine how costly this strategy is:

| | Has no costs | Has few costs | Is neutral | Has some costs | Has high costs |
|----------------|--------------|---------------|------------|----------------|----------------|
| This strategy: | | | | | |

What is your next step?

Continue to use the strategy, or

Modify the strategy in the following way: _____

Or, try the following new strategy: _____

WHERE TO GET HELP

In this final section of the chapter, we will outline some general tips and resources for developing a plan that will work for you. Table 2.2 is a checklist of questions to ask yourself, along with suggestions for the appropriate resources for finding help.

| Table 2.2: Identify Sources of Help to Manage Your Time and Energy | | |
|---|---|--|
| Question | Why your answer is important | Where to get the help you need |
| Are you exercising regularly? | It improves your fitness and helps you feel less tired | Consult a physical therapist |
| Do you eat the right foods? | The right diet can help keep your energy high | Consult a dietician |
| Can meditation reduce fatigue? | The right medication or combination of medications can make you more functional | Consult your physician |
| Have you evaluated your daily routines at home and work? | Energy conservation strategies can help you do things more efficiently | Consult an occupational therapist |
| Are you using the assistive devices you need? | Many devices can reduce the energy required for daily activities | Consult an occupational therapist |
| What are your cognitive strengths (and weaknesses)? | You can learn to build on your strengths and compensate for your weaknesses | Consult a neuropsychologist |
| Do you have a plan for organizing your daily activities? | Developing appropriate routines can increase your productivity | Consult an occupational therapist or speech-language pathologist |
| Do you ask for help when you need it? | Delegating tasks will give you more time and energy | See chapter 12 |

Do-It-Yourself Help

As with many people with MS, you may prefer to develop your own plans. Resources are certainly available for those who wish to do this. The National Multiple Sclerosis Society maintains an excellent Web site with educational material, research updates, and information about local resources. Another source of information is the popular press. In today's society, you are not alone in needing to manage your time and energy. There are a number of excellent resources written for the general public.

For example, Loehr and Schwartz (2003) suggest that the key to “full engagement” is to manage energy by balancing stress with periods of recovery. In another bestseller, David Allen (2001) suggests that your ability to get things done is directly proportional to your ability to relax. Further, he recommends that your stress can be reduced if you develop a “collection” system for the various things that you are going to do. Using a dependable system of reminders clears your mind, allows you to focus on accomplishing things, and ultimately reduces stress.

Caregivers

It may be necessary at some point for you to obtain ongoing assistance from a caregiver to get things done. Caregivers can be family members, friends, relatives, paid help, or a combination of all of these. Taking this step doesn’t necessarily mean that you will have a loss of independence. For successful and productive interactions with your caregiver(s), you may want to consider the following suggestions. (See chapter 12 for more details.)

Write a job description so that roles and responsibilities will be clear. Writing things down also will give both you and the caregiver a reference point. It is important to set guidelines about your important concerns (e.g., privacy or finance issues), and maintain as much as possible of your personal style.

Professional Help

Finally, consultation with professionals can be an excellent place to start seeking caregiving help. A review of table 2.2 will provide you with a series of suggestions. For example, consulting a physician who specializes in MS is a good way to learn about medications to enhance energy. Again, table 2.2 only provides examples; your local or the National Multiple Sclerosis Society can provide you with an appropriate referral based upon your clearly stated needs.

Conclusion

Getting things done is the work of living. In this chapter, we’ve outlined some of the aspects of MS that may challenge your ability to work—to get things done. Despite these challenges, it’s clear from the many people with MS whom we’ve interviewed that taking charge of your time and energy allows you to continue to do the things that you value. It is critical for you to set your own priorities, become aware of possible triggers for physical problems, and construct and evaluate a set of strategies that works for you.