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II

MANAGING MS SYMPTOMS

The new immune system medications provide true disease management for the first time. They clearly are not for everyone with MS and must be selected and used with expert advice. The backbone to MS management has been and continues to be the management of symptoms. Everyone with MS should be aware of the many ways that the symptoms of MS can be managed, with the goal of improved quality of life.

Symptoms in MS may be divided into those that are caused directly by demyelination within the brain and spinal cord and those that are not. Symptoms that are caused by the disease itself are called *primary* symptoms. If you lose myelin in the part of the brain or spinal cord that influences strength, you will develop weakness; if you lose myelin in the part that controls coordination, you will become uncoordinated; and if you lose myelin in the part that con-

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trols sensation, you will develop numbness, pain, burning, or itching. It is quite simple to understand that the number of combinations is endless. That is why no two people with MS are exactly alike.

Symptoms in MS may be divided into those that are caused directly by demyelination within the brain and spinal cord and those that are not.

People who have primary symptoms sometimes also suffer from problems that are only indirectly caused by the disease; these are called *secondary* symptoms. For example, some people who are weak and stiff develop decreased movement at the joints, which are called contractures, and immobility can lead to osteoporosis or skin breakdown.

Chronic disease may lead to changes in how one looks at life and tackles life's stresses. It may lead to depression, frustration, or vocational and marital problems. These are called *tertiary* symptoms.

Thus, to really tackle MS, the disease process should be modified whenever it is possible to do so; the symptoms of the disease should be managed to allow better function; and the person with the disease should be helped to improve his or her quality of life.

*C h a p t e r***3****FATIGUE**

To those who do not have MS, it may come as a surprise that fatigue is the most disabling symptom of MS. For those who have MS, this is not at all surprising. Part of the reason that fatigue is so common and potentially disabling relates to the fact that many different kinds of fatigue are experienced by people with MS, and it is possible to have none or all of the forms at the same time.

Obviously, MS does not protect you from the normal fatigue that anyone else may experience. However, a person with MS sometimes may have a “short-circuiting” type of fatigue. This occurs when a limb has weakness due to demyelination. If it is fatigued, the limb exhibits increased weakness due to demyelination. The limb will recover when the arm or leg is rested, but it may be bothersome when activities require its ongoing use. Repeatedly asking the demyelinated nerve to perform when it is repeatedly short-circuiting causes fatigue. The judicious use of aerobic exercise (see Chapter 20) may help build endurance, if not strength, and thus may decrease this form of fatigue. However overexercising with weights increases both fatigue and weakness, so a careful balance must be sought.

Management strategies include the appropriate use of exercise and rest, with the understanding that “no pain, no gain” is simply

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wrong and that rest should come before short-circuiting fatigue becomes significant.

If a person does not remain active, muscles atrophy and *deconditioning* occurs. This is another source of fatigue. Maintaining mobility is essential! The appropriate management strategy for this type of fatigue is exercise and maintaining of mobility. Depression (see also Chapter 22) may be associated with MS and may cause significant fatigue. This may result from not eating or sleeping well, or it may be associated with a general feeling of depression. It is essential to recognize that this fatigue is related to depression. It should be managed by aggressively treating the depression with medication and counseling.

The most common fatigue seen in MS is called *lassitude*. It is sometimes referred to as “MS fatigue.” Lassitude is characterized by an overwhelming sleepiness that may come on abruptly and severely at any time of day. This form of fatigue likely is biochemical in origin, and medications that modify brain chemistry may be helpful. Amantidine (Symmetrel[®]) is an example of a medication that affects the nervous system and also has antiviral effects. The antidepressants, including fluoxetine (Prozac[®]), paroxetine (Paxil[®]), and sertraline (Zoloft[®]), may be useful for this type of fatigue, even in those who are not depressed. These medications may not be interchangeable, with one working better for one person and a different one for another. Lassitude is a bothersome form of fatigue because a person may look well and yet not be able to function. A new, novel medication, modafinil (Provigil[®]) has been shown to decrease MS fatigue and has become a commonly used treatment for this problem. Its mode of action is not clear but it does work by altering the brain’s neurochemistry. This is becoming the most popular anti-fatigue drug in MS. It has a potential side effect of agitation, which should be reported to your physician immediately.

Stimulant medications sometimes may be necessary. These include pemoline (Cylert[®]), methylphenidate (Ritalin[®]), and occasionally dextroamphetamine (Dexedrine[®]). These medications

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should be used with caution because they may be habit-forming and may lead to agitation. A well-timed nap sometimes is most helpful in managing lassitude. The management strategy for this form of fatigue includes rest and the use of antidepressant and stimulant medications.

Even though fatigue is common and potentially disabling, it is clear that people who have MS are not fragile. Although rest may be helpful, the idea that fatigue leads to increased demyelination has not been proven. The idea that MS progression occurs if a person does not rest a great deal is also without merit. You need to listen to your body, but there always are times when a little extra push is necessary, and this is not a cause for fear.

In summary, the approach to fatigue in MS involves identifying the type of fatigue and treating it specifically. Removing any contributing causes is essential. These include infections, stress, and overutilization of some medications. While medications can help, rehabilitative techniques can also be valuable.

Occupational therapists may be helpful in teaching the concept of energy conservation to those who have moderate or severe fatigue of differing varieties. Efficiency in performing activities of daily living, which include dressing, grooming, toileting, eating, and so forth, may increase the energy available for other activities.

PRINCIPLES OF ENERGY CONSERVATION

- Balance activity with rest and learn to allow time to rest when planning a day's activities. *Rest means doing nothing at all.* There is a fine line between pushing to fatigue and stopping before it sets in. Rest improves overall endurance and leaves strength for enjoyable activities.
- Plan ahead. Make a daily or weekly schedule of activities to be done and spread heavy and light tasks throughout the day.
- Pace activity. Rest before you become exhausted. Taking time out for five- or ten-minute rest periods during an activ-

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ity may be difficult at first, but it may significantly increase overall functional endurance.

- Learn “activity tolerance.” See if a given activity can be broken down into a series of smaller tasks or if others can assist in its performance.
- Set priorities. Focus on items that are priorities or that must be done, and learn to let go of any guilt that may be associated with not finishing tasks as the result of fatigue.

MINIMIZING FATIGUE BY CONSERVING ENERGY

The following are some specific suggestions for common tasks and groups of tasks that most of us need to do regularly. They take advantage of the principles described previously and are designed to conserve energy expenditure.

Kitchen and Cooking Arrangements

- Store items that are used most often on shelves or in areas where they are within easy reach, to minimize the need to stretch and bend.
- Keep pots and pans near the stove, dishes and glasses near the sink or eating area.
- Keep heavy appliances such as toasters and blenders in a permanent place on countertops.
- Have various working levels in the kitchen area to accommodate different tasks, and evaluate working heights to maintain good posture and prevent fatigue. Sit whenever possible while preparing meals or washing dishes, and use a large stool with casters that roll to eliminate at least some walking. When standing for a prolonged period, ease tension in your back by keeping one foot on a step stool or an opened lower drawer.
- Use wheeled utility carts or trays to transport numerous and/or heavy items.
- Hang utensils on pegboards to provide easier accessibility.

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- Have vertical partitions placed inside storage spaces to permit upright stacking of pots and pans, lids, and baking equipment.
- If storage cabinets are deep and hard to reach, use lazy Susans or sliding drawers to bring supplies and utensils within easy reach.
- Use cookware designed for oven-to-table use to eliminate the need for extra serving pieces. Use paper towels, plastic wrap, and aluminum foil to minimize cleanup.

Meal Preparation

- Have good lighting and ventilation in the cooking area.
- Gather items needed to prepare a meal, and then sit while doing the actual food preparation.
- Select foods that require minimal preparation such as dehydrated, frozen, canned, or packaged mixes.
- Use a cutting board with nails to hold items that are being cut.
- Prepare double recipes, and freeze half for later use.
- Use electrical appliances rather than manual ones whenever possible, including food processors, mixers, blenders, and can openers.
- Use a microwave oven or crockpot to cut down on cooking and cleanup time.
- Bake rather than fry whenever possible.
- Bake cookies as sheets of squares instead of using shaped cutters.
- Slide heavy items along the countertop rather than lifting them.
- Use a damp dishcloth or a sticky substance such as Dycem™ to keep a pot or bowl in place while stirring.
- Line baking pans with foil to minimize cleanup, and soak pots and pans to eliminate scrubbing.

Cleaning

- Spread tasks out over a period of time; do one main job each day rather than an entire week's cleaning at one time.

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- Alternate heavy cleaning tasks with light ones, and either get help or break major heavy duty cleaning tasks into several steps.
- Use a pail or basket to transport cleaning supplies from room to room to save on the number of trips back and forth.
- Use adaptive equipment, such as extended handles for dusters or brushes, to avoid bending.

Laundry

- Wash one or two loads as they accumulate rather than doing multiple loads less often.
- Collect clothes in one place, and transfer them to the laundry area in a wheeled cart if possible.
- If the laundry area is in a basement, plan to remain there until the laundry is done, and have a place to relax while you are waiting.
- If a clothesline is used, have it hung at shoulder height, and place the laundry basket on a chair while hanging laundry.
- Hang clothes promptly after they are dry to minimize ironing.
- Sit down while ironing.
- Buy clothes that require minimal maintenance.

Shopping for Groceries

- Plan menus before going to the store, and take a shopping list with you.
- Use the same grocery store on a regular basis, and learn where various items are located for easier shopping; using a photocopied master grocery list organized to match the store layout is a simple way to minimize time and energy.
- Use home delivery whenever possible.

Bedroom Maintenance

- Put beds on rollers if they must be moved or keep them away from walls.

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- Make one side of a bed completely, then finish the other side, to minimize the amount of walking involved.
- Organize closets for easy access by making top shelves and clothing rods low enough to reach without straining.
- Use lightweight storage boxes, hanging zippered clothes bags, and plastic boxes for items that are needed daily.

Yardwork

- Alternate tasks and incorporate short rest periods to avoid fatigue.
- Keep your garden small and easy to manage.
- Use adaptive equipment, such as handles with extensions, to minimize bending.

Infant and Child Care

- Always use your leg and arm muscles rather than your back muscles when lifting an infant or child.
- Wash, change, and dress an infant at counter height.
- Kneel while washing a child in a bathtub.
- Use disposable diapers.
- Adapt the fasteners on a child's clothing for easier dressing.
- Have a child stand on a footstool while helping him or her dress or wash.

Sitting and Desk Work

- Arrange your desk and chair heights to facilitate maintaining proper posture, which reduces slumping of the shoulders and neck flexion.
- Use a chair that has good back support.
- Arrange your office so that your file cabinets, computer terminal, and other equipment are easily accessible.
- Use small lazy Susans on the desktop for pens, paper clips, tape, stapler, and so on.
- Use a phone device that allows the receiver to rest on your shoulder and frees your hands during extended conversations.

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Dressing

- Lay out clothing for the next day before retiring.
- Sit while dressing whenever possible.
- When dressing, dress the weaker side first; when undressing, undress the strong side first.
- Use a long-handled shoe horn.

Bathing

- Organize shampoo, soaps, and toiletries, and keep them together by the bathtub or shower.
- Use grab bars to assist in safely getting in and out of the bathtub.
- Use a tub bench or stool while showering or bathing.
- Always avoid hot water while bathing because it increases fatigue.