



Treating
**YOURSELF
WELL**

ANDREW, DIAGNOSED IN 2013

Most of us think of a “treatment” as something prescribed by our doctor to make a problem go away. For example, an antibiotic might be prescribed to treat an ear infection or pneumonia. When we take the medication according to the doctor’s instructions, the problem is cured and we feel like our old selves again.

“Treatment” in MS has a different meaning. Because a cure has not yet been found for MS, the interventions prescribed by physicians and other healthcare professionals who treat this disease are not designed to make MS go away. Instead, the various treatments, including medications, self-care strategies, exercises and adaptive aids are designed to slow disease progression, manage symptoms, maximize abilities and prevent complications. In another chapter, we have described the disease-modifying treatments that are prescribed to slow disease progression; this chapter describes the strategies for treating relapses (also called attacks or exacerbations) and managing symptoms, as well as the steps you can take to enhance your overall health and well-being.

The medical management of your MS will involve an ongoing collaboration between you and your healthcare provider(s). The physician (or other provider) will prescribe various treatments and support your efforts

to manage the disease and its symptoms in the most effective way. The information you provide, including your medical history, description of your symptoms, and periodic feedback about your response to particular medications, will help the doctor identify the most suitable treatments for you to use.

Management of relapses

A flare-up of symptoms lasting from 24 hours to several days or weeks — involving either the development of new symptoms or the worsening of old ones — may indicate a relapse or exacerbation of MS. An exacerbation of symptoms is usually accompanied by inflammation and demyelination in the central nervous system (CNS), either in new sites or old. If the attack is relatively mild and brief, the doctor may feel that no treatment is necessary. If symptoms reduce your ability to function, or continue to worsen, the doctor may prescribe a course of corticosteroids or adrenocorticotrophic hormone (ACTH) in an effort to reduce the inflammation and shorten the duration of the exacerbation.

Most exacerbations will eventually get better on their own even if no treatment is given; the goal is to manage the symptoms and accelerate recovery.

Symptom management

The symptoms that are caused by demyelination in the CNS will vary depending on where a lesion (plaque or scar) has occurred. The most common symptoms in MS include unusual fatigue, vision changes, mobility problems, stiffness or spasticity, sensory changes (numbness, tingling, or pain), bladder and/or bowel problems, changes in sexual function, mood changes and cognitive changes. These symptoms can occur at any point over the course of the illness, depending on the location of the demyelination. Over the course of the disease, a person may experience several of these symptoms or only a few. There are a variety of strategies to help you manage the symptoms that occur.

“I’ve felt tired before but this MS fatigue is really different. What is the best way to deal with it?”

Fatigue

One of the most common and annoying problems for people with MS is fatigue. MS-related fatigue can have a variety of causes:

- Muscle fatigue — the feeling of weakness or tiredness that can occur following physical activity or exercise — usually goes away after a period of rest.
- The tired feeling that can accompany depression typically subsides with some combination of psychotherapy and medication.
- The fatigue that results when a person’s sleep is disturbed by multiple trips to the bathroom or other uncomfortable symptoms is best addressed by treating those symptoms.
- The type of fatigue that is unique to MS is called lassitude — an overwhelming feeling of tiredness that can occur independent of the time of day, amount of rest or level of activity. Lassitude is best managed with a regimen of energy-management strategies, exercise and medication.

The best strategy for dealing effectively with the symptom of fatigue is to identify and address all of the factors that may be contributing to it, including sleep problems caused by other MS symptoms, impaired mobility or any other health issue. Listening to one’s own body is the best place to start. The rest schedule or medication that works effectively for one person will not necessarily work well for someone else.

In addition, many people with MS become sensitive to heat and/or humidity. An elevated body temperature (whether from fever, hot weather or activity) slows the conduction of nerve impulses. This can result in a temporary worsening (called a pseudo-exacerbation) of fatigue and other symptoms. Keeping the body cool with air conditioning, cool beverages, cooling devices or other cooling strategies can reduce this problem.

Vision problems

It is fairly common for people with MS to experience problems with their vision. The most common visual symptom — optic neuritis (inflammation in the optic nerve) — can cause eye pain, blurred vision (like looking through water or a window screen), vision loss, blind spots and reduced color sensitivity. Other visual symptoms include double vision, or tiny, rapid eye movements that make objects appear to jump around. Visual changes generally last for a few weeks and then improve. The doctor may recommend a short course of high-dose corticosteroids if the symptoms persist or cause discomfort. Although visual problems are a common first symptom of MS, they can occur at any time, or several times, over the course of the illness.

Problems with walking or mobility

Disturbances of gait and balance (caused by incoordination, weakness in one or more limbs, numbness of the feet, dizziness, or spasticity) are common in MS. Difficulty in walking may worsen during exacerbations, and then improve or clear completely as the attack subsides. Or, gait problems may gradually worsen over time. A physical therapist can evaluate the mobility problem and provide gait training, exercises to regulate tone and strengthen muscles, and training in the use of mobility aids such as a cane or crutch. The physician may also prescribe medication(s) to improve walking speed or to treat sensory symptoms or spasticity that are interfering with a person's ability to walk comfortably.

Spasticity

Normally, movement in the body is produced by muscles that contract and relax in a coordinated manner. When nerve function is impaired by MS, too many muscles contract at the same time, resulting in increased muscle tone and a resistance to movement. This is called spasticity. As a result of spasticity, a person's limbs (most often the legs) begin to feel stiff and heavy. More energy is required to move the muscles, making walking

tiring and more difficult. The stiffness may be worse at night or after sitting for an extended period of time, and may sometimes be accompanied by uncomfortable muscle spasms.

By reducing spasticity, the person can experience greater freedom of movement and strength, as well as less fatigue and more coordination. Spasticity reduction can be accomplished through stretching and range-of-motion exercises and the use of medication.

Sensory symptoms

Many people with MS experience annoying or uncomfortable sensations in various parts of their body.

Numbness, tingling, “pins and needles,” a burning sensation and coldness are some of the more common sensory changes that people report. Numbness is most often felt in the lower legs and feet, or the arms and hands, but it can rise from the legs to the upper abdomen. Numbness can also occur on one side of the face or the tongue. While sensory symptoms are considered to be “benign”— in other words more annoying than disabling — they can cause difficulties in everyday life. Numbness or tingling in the hands may cause people to drop things or be unable to tell what they have in their hands; sensory changes in the feet can cause clumsiness, balance problems and difficulty driving.

While little can be done to treat numbness, uncomfortable burning sensations and heightened skin sensitivity can be treated effectively with medication.

The types of pain that have been associated with MS include burning sensations, headaches, eye pain, shooting pain in the limbs and sharp facial pain, among others. Report pain to your physician so that the cause can be identified and the proper treatment prescribed. Some of the treatments for MS-related pain include physical therapy, relaxation techniques, massage and medication.

Bladder control problems

The neurologic changes that occur in MS sometimes interfere with bladder function. While these changes can be distressing — and occasionally disabling — they can be managed quite effectively with a treatment regimen that includes diagnostic testing, education, medication and self-care activities. The most common bladder problems in MS include a failure to store urine properly, a failure to empty the bladder completely or some combination of the two. These problems may result in the following symptoms: urinary urgency (the need to get to the bathroom quickly), urinary frequency (feeling the need to urinate frequently), nocturia (being awakened at night by the need to

urinate), dribbling, and, occasionally, incontinence (wetting oneself). One self-prescribed solution to bladder control problems may be to restrict fluid intake. While this strategy may be helpful in the evening hours to reduce nocturia, severely restricting fluids all day long can lead to bladder infections, constipation and dehydration.

More effective bladder management strategies make use of lifestyle modifications, pelvic floor physical therapy, and behavioral techniques such as bladder training. In addition, certain medications that block muscle contractions in the bladder are beneficial in treating urgency, frequency and incontinence. Although men and women are sometimes reluctant to discuss bladder symptoms with their physician, doctors who treat MS have the knowledge and expertise to deal with these problems. Effective bladder management gives people a greater sense of freedom and control and reduces the risk of urinary tract infections.

Bowel control problems

Bowel symptoms are less common in MS than bladder problems, but can be just as distressing and disruptive. In most instances, they can be effectively managed with some simple strategies. The most common bowel symptom in MS is constipation. The primary

strategies for controlling constipation include a regular and consistent bowel schedule, a diet that is high in fiber, and adequate fluid intake. Developing a healthy bowel routine may take some time, but consistency and periodic re-evaluation of the bowel management program are the keys to success. People who are unaware that their constipation is MS-related may neglect to mention it to the doctor. In the early days of MS, as you are getting to know more about the disease and its effects on your body, mention any significant changes to the doctor or nurse. They can tell you whether or not a particular problem or change is related to the MS and what measures you should take to correct it.

Problems with balance and coordination

Problems with coordination — particularly tremors — are caused by demyelination in the cerebellum. While there are no medications to address these symptoms, rehabilitative strategies such as physical therapy and the use of assistive devices can be helpful. Problems with balance can be caused by damage in the cerebellum or in the vestibular system (inner ear) or connections to the vestibular system. Careful evaluation of the problem is needed to identify the source of the symptoms.



Kellen (right), diagnosed in 2010

Changes in sexual function

Men and women with MS can experience sexual changes for several reasons: 1) as a direct result of demyelination in the brain and spinal cord; 2) as a result of symptoms like fatigue, spasticity and depression that can interfere with sexual interest or activity; or 3) because of emotional reactions they are having to life changes caused by MS. Some of the medications that people take can also interfere with sexual arousal or activity. For these reasons, people with MS may find that their sexual lives are affected in a variety of ways. At one time or another, both men and women may report feeling less sexually interested or aroused. For men, erectile difficulties are the most common symptom; for women, changes in sensation, vaginal lubrication and ability to achieve orgasm are the most frequently reported.

Through accurate diagnosis, treatment and counseling, individuals and couples can learn how to manage these sexual changes. The counseling can help people communicate more effectively and learn new ways to express themselves sexually, while a variety of products and medications are available to relieve some of the symptoms.

Sexual changes are the problem least likely to be mentioned by people with MS or their healthcare provider. Do not hesitate to bring these problems to your healthcare provider's attention. There is help available in the form of reading materials and consultations with specialists. The National MS Society can also direct you to resources in your area.

Depression

Depression is very common in MS — more common, in fact, than in other chronic diseases. While it may seem obvious that a person diagnosed with a chronic illness like MS could easily become depressed about it, the research suggests that the depression seen in MS is a symptom of the disease as well as a reaction to it. In fact, depression is one of the most common symptoms of MS. That means that a person with MS could become depressed at any time — earlier or later in the disease — even in the absence of significant physical symptoms or disability.

It is not a sign of weakness or inadequacy. Studies have shown that at least 50 percent of people with MS will experience an episode of depression at some point in their lives. These episodes of depression can be distinguished from the normal grieving described in the chapter on **Taking the First Steps**. While grief will ebb and flow with the life changes caused by MS, depression involves very specific symptoms* that last most of every day for at least a couple of weeks. Let your healthcare professional know if you are

*Persistent sadness, loss of interest or pleasure in activities, fatigue or loss of energy, problems with concentration, feelings of worthlessness, irritability, restlessness or significant slowing, significant weight change up or down, sleeping too much or too little, recurrent thoughts of death.

experiencing a significant and persistent change in your mood. Depression is not only one of the most common symptoms in MS, it is also among the most treatable, and meeting the challenges of MS is difficult enough without trying to do it while feeling depressed.

Two questions to ask yourself:

1. During the past two weeks, have you often felt down, depressed or hopeless?
2. During the past two weeks, have you had little interest or pleasure in doing things?

If you answered “yes” to either or both of these questions, you may be experiencing depression. You can connect with an MS Navigator® for help, information, or assistance finding a mental health professional in your area, call 1-800-344-4867.

“What is the likelihood that I’ll experience changes in my thinking and in my memory? This is pretty frightening for me.”

Intellectual impairment

Until the 1980's, there was little recognition, even among MS professionals, of cognitive impairment in MS. We now know that lesions in the brain and loss of brain tissue (atrophy) can cause problems with memory, thinking, problem-solving and other thought processes, in the same way that they can cause physical changes.

Research has shown that 60 to 65 percent of people with MS will experience some changes in one or more of their intellectual functions. For most people the changes are relatively mild and easily managed with a variety of organizational strategies. Approximately 10 percent of people with MS will experience more severe impairments that can interfere with important daily activities at home and at work.

The changes most often reported by people with MS are with memory — primarily for recent events. Other areas that may be affected include: the ability to focus attention and concentrate on a given activity or more than one activity at a time; organizational and planning skills; problem-solving abilities; verbal fluency (word-finding); the understanding of visuo-spatial relationships (e.g., right-left discrimination), and the speed of information processing. A slowing of information processing speed is

particularly important because it tends to affect all of the other intellectual processes. People who experience this kind of slowing report that they can still do everything they used to be able to do, but it takes them significantly longer to think through the required steps.

MS-related cognitive symptoms can occur at any time over the course of the disease, even at the very beginning. In addition, there seems to be no relationship between physical disability and cognitive impairment; a person with only minimal physical problems can become quite impaired intellectually, and a person with severe physical disability can have no cognitive problems whatsoever.

There is much that can be done to deal with intellectual changes. People who experience changes can begin immediately to learn strategies to minimize their impact on life activities. Along with fatigue, cognitive changes are known to be a primary reason why people leave the workforce. The earlier the treatment interventions are begun, the greater a person's ability to make use of effective strategies on the job.

Many of the initial changes that people begin to notice in themselves may not be recognized by the doctor during an office visit. Do not hesitate to bring to your doctor's attention any problem or change that is of concern to you or your family members. If your doctor is unable

to refer you to a neuropsychologist or other professional with expertise in the area, you can get a referral from the National MS Society.

Considering alternative and complementary treatments

There are a variety of treatments available outside the mainstream of medicine. These alternative therapies, which are offered by chiropractors, homeopaths, naturopaths, herbalists, psychic healers, reflexologists and many others, may seem very appealing to you, however, you must be an informed and cautious consumer. Many of these treatments have never been scientifically tested and may actually be more harmful than helpful in the treatment of MS.

Some methods of treatment may make you feel better, like a satisfying massage or a healthy diet, but are not specifically aimed at curing MS or reducing disease activity. Any intervention of this type, which impacts general health and promotes “wellness,” is considered “complementary” to the medical treatments prescribed by your physician. In other words, these wellness measures should be used along with prescribed medical treatments rather than as a

replacement for them. Discuss these options with your physician and educate yourself on the potential risks and benefits. In addition, the National MS Society can provide you with up-to-date information about available treatment options in MS care.

Enhancing your health and wellness

Having read about the many ways to manage MS and the symptoms it can cause, you may be concerned that you will never again think of yourself as a well person. There are, however, a variety of steps you can take to ensure your general health and feel your best. Don't become so preoccupied with your MS that you neglect other aspects of your well-being. Like people living without MS, you can enhance your wellness by adopting the following preventive health strategies:

- **Eating a healthy diet** — The USDA's Dietary Guidelines for Americans emphasize a low-fat diet rich in fresh fruits, vegetables and whole grains. Individuals with low levels of vitamin D should increase their intake of foods rich in vitamin D and take supplements if needed. Calcium supplementation is recommended for post-menopausal women and anyone with limited mobility. Other vitamin or mineral



Michelle, diagnosed in 2001

supplements have not been found to alter the disease course of MS, and no other types of diet have been found to be of special benefit for people with MS. Learn more at nationalMSSociety.org/diet.

- **Getting adequate exercise** — Several studies have demonstrated that regular aerobic conditioning and resistance training, geared to a person's abilities and limitations, help people with MS improve their muscle fitness and strength, reduce fatigue, and enhance mood and quality of life. The National MS Society can refer you to MS specialist clinicians who can recommend an appropriate exercise regimen for you.

- **Cigarette smoking** — While the negative health effects of smoking such as respiratory, cardiovascular and cancer risk are well known, several studies over the past several years, have indicated that cigarette smoking also increases the likelihood of disease progression in MS. Learn more at nationalMSSociety.org/smoking.
- **Getting sufficient rest** — In MS, a variety of things can interfere with a good night's sleep. Be sure to discuss with your healthcare professionals any symptoms — such as stiffness, pain or urinary problems — which disrupt your sleep. Building brief rest periods into your day can also help reduce feelings of fatigue and maximize your energy. Learn more at nationalMSSociety.org/sleep.

- **Utilizing effective stress management strategies** — Daily life brings with it a variety of stresses, particularly when MS becomes part of the picture. While the exact relationship between stress and MS remains unclear, learning how to manage life's stresses more comfortably helps everyone feel better. Stress management takes different forms for different people (e.g., meditation, yoga, listening to music, social time with friends, maintaining a stress log); the goal is to find the strategy that works best for you.
- **Having regular medical checkups and screening tests** — People with MS and their physicians have a tendency to focus on the MS to the exclusion of other health issues. Your annual screening should include a medical history, physical examination, and any laboratory or screening tests (e.g., Pap smears and mammograms for women, prostate and testicular exams for men, blood tests) that are recommended based on your age and other risk factors. Unfortunately, a diagnosis of MS does not protect anyone from other health problems. The Society's **Preventive Care Recommendations for Adults with MS** provides a chart detailing the medical tests, vaccinations, and general health and safety rules recommended for all adults with MS.
- **Developing an effective support system** — As you begin learning to live your life with MS, make sure

you have a good support network in place — no one needs to do this alone. In addition to your family and friends, you will add some trusted healthcare providers to your “team,” as well as the National MS Society and other community resources.

- **Paying attention to your emotional and spiritual needs** — People can sometimes become so focused on treating their MS that they forget their equally important inner needs. Identifying and attending to these needs will not only help you to feel your very best, but ensure that you have the emotional resources you need to deal with the new challenges in your life.

Together, the symptom management strategies and the preventive health strategies described in **Knowledge Is Power** can help you to feel your very best while living with MS.

Another helpful resource is the Society's **Wellness Discussion Guide for People with MS and their Healthcare Providers**. This guide is designed to help facilitate conversations with your doctor about wellness strategies related to diet, exercise and emotional wellbeing, and about preventive healthcare and the use of complementary and alternative therapies. To learn more, visit nationalMSSociety.org/wellnessguide.

Things to think about

- While this brief overview of symptoms and treatments may be overwhelming, remember that no two people have identical symptoms. You may or may not experience the symptoms described here.
- By educating yourself about the possible symptoms of MS, you will feel more prepared and less frightened when, and if, you experience one of them.
- You will get a lot of well-meaning advice from friends and relatives. Keep in mind that your best sources of accurate, reliable and up-to-date information about treatments in MS are your healthcare providers and the National MS Society.
- People can be healthy and well in spite of having MS.

Resources

Thousands of resources, pieces of information and shared experiences about MS are available in print and on the internet. Some of the information you come across may be strictly experiential, anecdotal, unsupported or even inaccurate. Always consider the source; ask your healthcare provider or the National MS Society to help you identify credible resources.

From the National MS Society

For answers to questions about MS and its management, contact the National MS Society at 1-800-344-4867 or visit nationalMSSociety.org or the following topic-specific pages:

- nationalMSSociety.org/Living-Well-With-MS
- nationalMSSociety.org/symptoms
- nationalMSSociety.org/treatments
- nationalMSSociety.org/healthy
- nationalMSSociety.org/meds
- nationalMSSociety.org/wellnessguide
- nationalMSSociety.org/KIPwell

The Society produces many other resources about various aspects of MS. These resources are available online or call 1-800-344-4867 to request.

- nationalMSSociety.org/educationalvideos
(also at youtube.com/nationalMSSociety)
- nationalMSSociety.org/brochures
(or see the Catalog of Informational Resources mailed with this book if you received it by mail)

Books

Books may be available at bookstores and/or online booksellers.

- Bowling AC. **Complementary and Alternative Medicine and Multiple Sclerosis** (2nd ed.) (2007). (NY:DemosHealth)
- Ettinger AB, Weisbrot DM. **The Essential Patient Handbook** (2004). (NY:DemosHealth)
- Murray TJ, Saunders C, Holland N. **Multiple Sclerosis: A Guide for the Newly Diagnosed** (4rd ed.) (2012). (NY:DemosHealth)
- Kalb R (ed.). **Multiple Sclerosis: A Guide for Families** (3rd ed.) (2006). (NY:DemosHealth)
- Kalb R, Giesser B, Costello K. **Multiple Sclerosis for Dummies** (2nd Ed). (NJ:Wiley) (2012).
- Kalb R (ed.). **Multiple Sclerosis: The Questions You Have; The Answers You Need** (5th ed.) (2012). (NY:DemosHealth)
- Kraft G, Catanzaro M. **Living with Multiple Sclerosis: A Wellness Approach** (2nd ed.) (2000). (NY:DemosHealth)
- Lowenstein N. **Fighting Fatigue in Multiple Sclerosis** (2009). (NY:DemosHealth)
- Schapiro RT. **Managing the Symptoms of Multiple Sclerosis** (5th ed.) (2007). (NY:DemosHealth)
- Schwarz SP. **300 Tips for Making Life with Multiple Sclerosis Easier** (2006). (NY:DemosHealth)
- Torkelson C. **Get Fit While You Sit** (1999). (Alameda, CA: Hunter House)

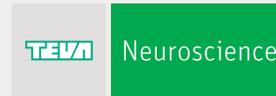
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The National MS Society’s mission is for people affected by MS to live their best lives as we stop MS in its tracks, restore what has been lost and end MS forever. To fulfill this mission, the Society funds cutting-edge research, drives change through advocacy, facilitates professional education, collaborates with MS organizations around the world, and provides services designed to help people with MS and their families move their lives forward.

The National Multiple Sclerosis Society (“Society”) is proud to be a source of information on multiple sclerosis related topics. The information provided is based on professional advice, published experience, and expert opinion, but does not constitute medical or legal advice. For specific medical advice, consult a qualified physician. For specific legal advice, consult a qualified attorney.

The Society does not endorse products, services or manufacturers. Such names appear here solely because they are considered helpful information. The Society assumes no liability for the recipient’s use of any product or service mentioned. The Society does not independently verify whether the information provided by each service provider is accurate. The Society undertakes no responsibility to verify whether the service provider is appropriately licensed and certified and has applicable insurance coverage.

Early and ongoing treatment with an FDA-approved therapy can make a difference for people with multiple sclerosis. Learn about your options by talking to your healthcare professional and contacting the National MS Society at **nationalMSsociety.org** or 1-800-344-4867.



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1-800-344-4867