

Acknowledgments

The National Multiple Sclerosis Society and the Multiple Sclerosis Society of Canada wish to acknowledge the support of the physicians, researchers, therapists, nursing staff and support staff from the following institutions:

- MS Center at Holy Name Medical Center, Teaneck, N.J.
- Sunnybrook Health Sciences Centre, Toronto State
- University of Washington, Seattle

We'd also like to thank the following individuals for so graciously giving their time and sharing their stories with us:

- Ann Marie Johnson
- Maria Reyes-Velarde
- David Rosen

Author

Laurie Budgar was the editor of **Momentum**, the magazine of the National MS Society, from 2012–2017. She authored the original Society book, “Mood and Cognition in MS: What You Can Do,” from which this publication is excerpted and updated. Budgar specializes in health-related writing and editing, and is also a certified speech-language pathologist.

Preface

Though clinicians noted **mood changes** associated with multiple sclerosis as early as the 19th century, symptoms associated with mood disorder have only recently begun to receive the same degree of attention from clinicians as physical symptoms. Mood disorder is a complex issue and despite greater awareness, continues to be under-diagnosed and under-treated. This “invisible symptom” can be a direct result of the disease process, and can change over time.

We now understand that mood and physical functioning are intricately entwined, and treating one area often brings profound improvement to other aspects of an individual’s life—and to the lives of their families.

We also now recognize that while changes in mood may not be readily apparent to outside observers, their impact on a person’s life can be profound, affecting physical, social, emotional, occupational and spiritual functioning.

Fortunately, mood changes are among the most treatable symptoms of MS. With the appropriate strategies and tools in place, people with MS can live their best lives and participate actively in their own care.

This book and the accompanying video explore why and how people with MS experience changes in mood, and provide the latest information on how these symptoms can be addressed—from physical activity, medications and counseling to self-management strategies. In the video portion of the program, you will hear from clinicians at the forefront of MS research and treatment discussing the latest advances and recommendations, as well as from individuals who have experienced these symptoms and have lessons to share.

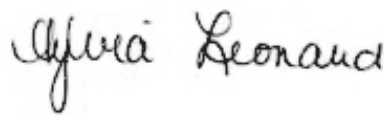
This book provides an overview of the types of mood changes common to MS, and further outlines the most successful ways that individuals, researchers and clinicians have developed for approaching these challenges. At the back of this booklet, you’ll find resources for learning even more about these topics.

We hope you find the program informative and engaging. For further information, visit **nationalMSSociety.org** or **mssociety.ca**, or call 1-800-344-4867 (U.S.) or 1-800-268-7582 (Canada).

Best regards,



Executive Vice President, Services
National MS Society



Interim President & CEO
MS Society of Canada

What's Inside

Personal Stories	2
Presenters	3
Mood Changes In MS	5
Grief	7
Depression.....	8
Who Gets Depression?.....	9
Lifting the Darkness.....	11
Anxiety	14
Moodiness and Irritability	15
Bipolar Disorder	16
Pseudobulbar Affect	17
Moods Matter—to Everyone	18
Current Research	21
Fatigue and Mood	22
Fatigue and Depression.....	23
Managing Fatigue	24
Summary	25
Resources	26
United States Resources	26
Canadian Resources.....	27
Additional Reading.....	28
Glossary	29

Personal Stories

Ann Marie Johnson

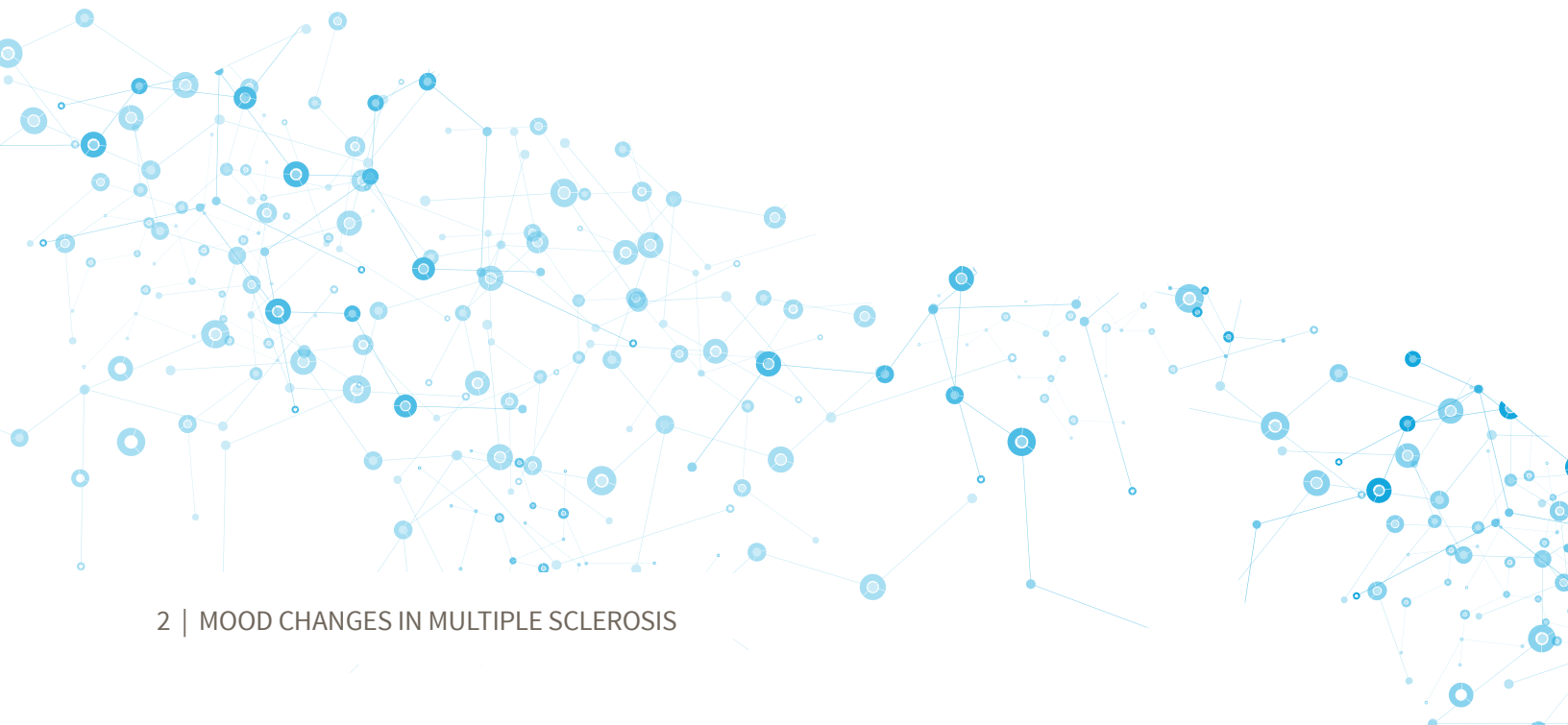
Diagnosed with relapsing-remitting MS in 2002

Ann Marie says she feels blessed to be free from visible MS symptoms most of the time. However, she experiences pain almost daily, and last summer began experiencing significant mood changes likely caused by her MS. Prior to beginning treatment for depression, Ann Marie retreated into isolation, but has since regained her physically and socially active life as a single woman. She enjoys her work with developmentally disabled adults, as well as going for drives, practicing yoga and otherwise getting out to “see the world.”

Maria Reyes-Velarde

Diagnosed with MS in 2000

Maria’s diagnosis has transitioned from an initial **relapsing-remitting** course of MS to secondary progressive MS. Maria first noticed mood changes from MS several years ago when conversations with her husband, which would typically be calm, increasingly became arguments. To help mitigate the mood-dampening effects of being home alone while her husband works, Maria adopted a small dog, Bon-Bon, that is now certified as an emotional-support animal. Maria maintains a website called “Hablemos de Esclerosis Múltiple” (Let’s Talk About Multiple Sclerosis), where she shares thoughts, experiences and information about MS in Spanish and English, and from her dual perspectives as a trained physician and as a person living with MS.



David Rosen

Diagnosed with relapsing-remitting MS in 2016

As David reflects on the years and months leading up to his 2016 diagnosis with MS, he remembers times when his mood became different, even “wacky.” His symptoms have prompted him to “change who I've been and what I've done, to be more of a stay-at-home father and really spend my time with my family.” David and his wife, Staci, stay active with their two young children who play team sports, traveling as a family with their camper, as well as raising chickens. David tries to focus on the positive aspects of his life, crediting much of his success in that area to Staci and their children.

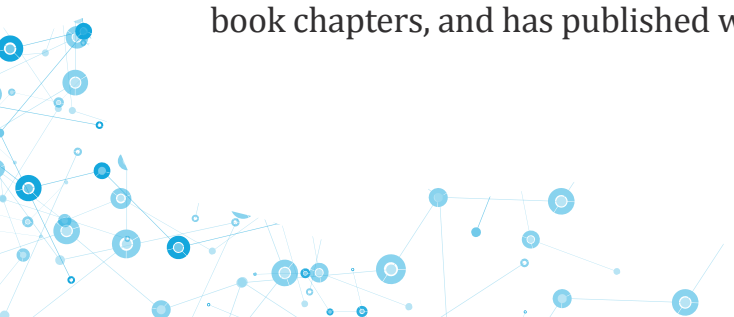
Presenters

Charles Bombardier, PhD

Charles Bombardier, PhD, is a clinical psychologist and a professor in the Department of Rehabilitation Medicine at the University of Washington in Seattle. He is also associate editor of the **Journal of Spinal Cord Medicine** and editorial review board member for **Rehabilitation Psychology**. Dr. Bombardier is a National MS Society-funded researcher. He has published numerous peer-reviewed journal articles on multiple sclerosis, including several on mood changes and MS, as well as exercise and MS. His awards include The Elizabeth and Henry Licht Award for Excellence in Scientific Writing from the American Congress of Rehabilitation Medicine.

Anthony Feinstein, MD, PhD

Dr. Anthony Feinstein, MD, PhD, is currently a professor of psychiatry at the University of Toronto, and is chair of the Medical Advisory Committee of the MS Society of Canada. His research focuses on identifying areas of the brain that are correlated with behavior in MS, traumatic brain injury and other disorders. In 2000–2001, he was awarded a Guggenheim Fellowship to study mental health issues in post-apartheid Namibia. This led to the development of that country's first rating scale for mental illness. Subsequent work in Botswana produced that country's first rating scale for mental illness as well. Dr. Feinstein has authored **The Clinical Neuropsychiatry of Multiple Sclerosis**, as well as other books and book chapters, and has published widely in peer-reviewed journals.



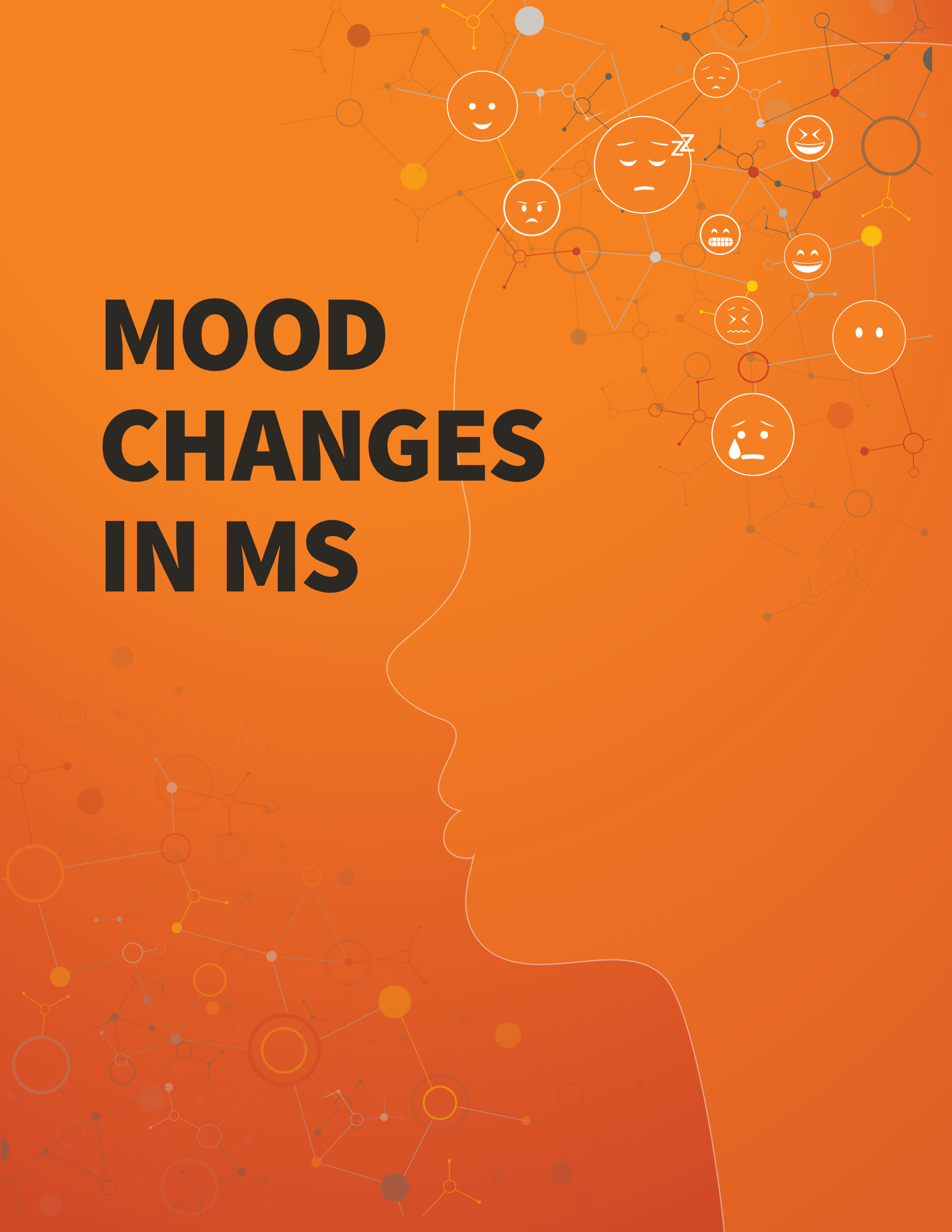
Frederick Foley, PhD

Frederick Foley, PhD, is a clinical psychologist, a professor of psychology at Yeshiva University in Bronx, N.Y., and director of Neuropsychology and Psychosocial Research at the MS Center at Holy Name Medical Center in Teaneck, N.J. He has dedicated his career to improving rehabilitation in MS. His research projects have focused broadly on developing outcome measures and psychosocial treatments for depression, cognitive function and sexual function in MS. He has authored or co-authored more than 90 publications in journals and books on MS. Dr. Foley lectures internationally on psychosocial issues in MS, and has received awards from the Academy of Psychosomatic Medicine and the Consortium of Multiple Sclerosis Centers for his contributions to MS research. He has served on the New Jersey Clinical Advisory Committee of the National MS Society, and in a variety of positions (including president) on the board of the Consortium of Multiple Sclerosis Centers.

Lauren Krupp, MD

Dr. Lauren Krupp has specialized in the area of multiple sclerosis for more than 30 years, and is a recognized authority in the care of children and adults with MS. Dr. Krupp leads the NYU Langone's Multiple Sclerosis Comprehensive Care Center. She founded the International Pediatric MS Study Group, and is a founding member of the International Multiple Sclerosis Cognition Society. Dr. Krupp is a National MS Society-funded researcher. She has directed clinical trials supported by the Society and the National Institutes of Health to improve fatigue, memory and reasoning among individuals living with MS, and has published more than 100 articles on MS.

MOOD CHANGES IN MS



For many people, a diagnosis of multiple sclerosis comes after a lengthy series of tests to find the underlying thread among seemingly unrelated physical symptoms, such as blurred vision, overwhelming fatigue, numbness in the hands or feet, or difficulty walking. While these physical issues are often the first to develop and the most noticeable, there are other, subtler aspects of MS that can greatly affect one's life. These include changes such as difficulty with memory and attention and concentration; and alterations in mood, such as depression or anxiety. These changes are very common.

Though these symptoms can be “invisible” to others, they can have a very real and profound effect on lifestyle, employment and relationships, as people struggle to plan, organize or remember important details or events, perform well at work or school, and stay engaged in their social and personal lives. Relationships between family members may be particularly affected, as spouses and children struggle to understand changes in the behavior of their loved one.

These symptoms don't exist in isolation. Mood changes can make some physical symptoms of MS, such as fatigue or pain, feel worse. Conversely, symptoms like chronic pain can dampen a person's mood.

Changes in mood and thinking, as part of the overall picture of MS, were first noticed by neurologist Jean-Martin Charcot in 1868. Nevertheless, physicians

and researchers continued to focus on the physical symptoms of the disease until the middle of the 20th century, when they finally began examining cognition, mood and fatigue, and the interactions between them. As a result, there's a growing awareness that managing these invisible symptoms helps people with MS better manage their physical symptoms, participate in their own care, and create a more empowered life.

Mood reflects the way a person is feeling emotionally at any given time, often in response to external events or physical concerns. Sometimes, moods are predictable: The long-anticipated birth of a child leads to feelings of joy and pride, perhaps mixed with anxiety or hope for the future; a leisurely afternoon with a friend makes us feel happy, content or loved; an argument with a family member leaves us angry, sad or upset.

“I was directing a meeting, and my eyes start bawling up and watering. **And I'm crying. But I can't figure out why,**” David Rosen says of an experience during the months leading up to his official diagnosis with MS in 2016. “Crying is not something typical of me. **I'm the type of person who could control emotions well.**”



People who have been recently diagnosed with MS, or whose abilities have recently changed, may find that their moods shift as they adapt to their new realities. Mood changes also can occur as part of the disease process, depending on which parts of a person's brain are impacted. A large-scale study from Canada (Marrie, et al, **Neurology**, 2015) suggested that people with MS have higher rates of anxiety, bipolar disorder, depression and schizophrenia compared to people without MS.

Some of the most common mood changes that may affect a person with MS are described below.

Grief

For many people, a diagnosis of MS comes during their 20s or 30s, just as they are establishing their identities in many aspects of their adult lives—in their careers, in their relationships, in their roles as parents, and in their mastery of life skills. When they learn that they have a chronic and incurable disease, it's both natural and expected that they will go through a period of grief as they come to terms with the losses that surround them, and the reality that things will never be the same as they once were.

"People can experience a sense of yearning for what they used to have—a kind of disbelief about what is happening to them," says Charles Bombardier, PhD, a clinical psychologist and a professor in the Department of Rehabilitation

Medicine at the University of Washington in Seattle.

But grief doesn't happen only in the first weeks and months after diagnosis. It can ebb and flow each time a person's abilities change over the course of the disease. Whether it's a change in vision, mobility, self-care, memory or anything else—something critical to a person's sense of who they are in the world has been altered.

That's what happened for Ann Marie Johnson, of Brooklyn, N.Y., who was diagnosed with **relapsing-remitting MS** in 2002.

"When I was first diagnosed, **the very thing that defines me was threatened,**" she says. "I couldn't walk. I had a cane. I was wearing flats." Ann Marie, who is known among her friends and colleagues for her love of skyscraper heels, began to worry: "Would I ever be able to walk again? Would I ever be able to wear my stilettos again? Some people may think that's an issue of vanity, but **there's an element of femininity that I wanted to keep.**"



And it wasn't just about shoes; on bad days, when her **fine motor control** was particularly affected, she couldn't apply makeup, curl her hair or put on earrings. "And all this is part of being a woman. And that was being threatened." Ann Marie grieved that deeply. "It also brings into play questions like, 'Will anybody love me like this?'"

The emotions that grief stirs up often are similar to what someone experiences after the death of a loved one; however, people don't necessarily experience the "five stages of grief" that many people have been taught, says Dr. Bombardier. Instead, he says, there are often two main phases: "The first is an intrusive phase, where something really bad happens. You are feeling very pained, an intense loss. You kind of catastrophize, like 'My life is over. I'll never be able to have what I want in life.'"

In the second phase, Dr. Bombardier says, people experience a type of denial. "Like, 'I don't need to take my **disease-modifying therapy** (DMT)—things are going to be OK.' People shift into not even believing that these bad things are there." But the phases aren't linear, he says. "It's a process of going back and forth. Sometimes you feel totally overwhelmed. Other times you can't stand that any longer so you shift away and think, 'I don't have to worry about this; I'll be fine.' And this going back and forth may be part of the healing process for people."

Grief is healthy and normal, and people should allow it free expression in whatever manner is most effective for them. Many people find it helpful to talk through these feelings with a counselor as soon as they arise. If grief persists for weeks or months, however, without lessening or without periods of happiness or enjoyment, it should definitely be professionally addressed, as it could be transforming into clinical depression.

Depression

It's common to hear people use the phrase "I'm so depressed," perhaps when their favorite sports team loses or when a date doesn't work out. But in truth, depression involves more than just a temporary feeling of sadness or disappointment, or even a period of "blues" that lasts a few days. Usually, those emotional states lift when something pleasant happens.

Though feelings of sadness or irritability are the most recognizable characteristics, depression also involves a loss of interest in activities that once brought enjoyment, such as hobbies, time with friends or sexual activity; depression can also bring about physical symptoms, such as changes in appetite, sleep, energy level and ability to concentrate. Depression is not really the opposite of happiness; it is the opposite of vitality. The specific symptoms will vary with each individual, however, just as the symptoms of MS itself will vary.

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 one or both of these questions, it could be an indication that you are experiencing depression. It is important to inform your healthcare team of how you are feeling.

For Ann Marie, grief did evolve into depression. She says that on days when her MS symptoms were worse, some things just didn't get done. And one day, it was just too difficult for Ann Marie, normally a very social and active person, to go out. "And then one day became many days. It became many weeks of just not wanting to go out."

Ann Marie also abandoned the activities she always enjoyed—cooking, walking by the water, going for long drives, even simple activities like making a smoothie on the weekends. But during her depression, she recalls, she didn't want to do any of it. "When I look back," she says, "I realize, there was almost a whole summer I didn't do anything."

Then one day, when her doctor asked her how she was feeling, she realized

it had been months since she had felt like herself. "I only had this feeling of not wanting to go out, not wanting to be with friends, not wanting to do much of anything but be in my bed, underneath the covers, and just turn off my brain and not think about anything."

Who Gets Depression?

Depression is one of the most common experiences among people with MS. Sometimes, depression occurs as a reaction to living with the disease and adjusting to a new reality. People who react to difficulties in an emotion-focused way are more prone to developing depression, explains Dr. Anthony Feinstein, a professor of psychiatry at the University of Toronto, and chair of the Medical Advisory Committee of the MS Society of Canada. Those whose coping style is more solution-based—with a greater emphasis on solving problems and challenges as they occur—are less likely to develop depression, he says.

Half of all people with MS will experience a major depressive episode at some point in their lives—a rate that's higher than in the general population or in other chronic diseases.



Often, depression occurs as a result of the changes in the brain that MS causes, and is unrelated to personal characteristics. Depression does not seem to be linked to the severity of a person's MS, either. That said, each individual's experience of depression is different, just as it is with other symptoms of MS. For example, depression can range from mild to severe and can occur at any point in the disease course.

Results from a 2014 study published in the journal **Human Brain Mapping** (Sicotte, Gold, et al), suggest that depression in MS may in fact have a biological basis. The researchers found that women with MS who exhibit depression also have significant loss of tissue in the **hippocampus**, an area of the brain closely associated with memory and mood. What's more, the researchers found that a very specific part of the hippocampus—the part that is responsible for depressed mood and loss of interest, rather than fatigue, impaired sleep and other physiological signs of depression—was affected in these women. (Not enough men were included in the study to determine if the same is true for them.) The bottom line is that researchers were able to demonstrate that low mood in women with MS is directly correlated with physical changes in the brain, and is not a failure of willpower, strength or any other character trait. The National MS Society is funding continued research in this area.

According to Dr. Feinstein, Stefan Gold, one of the researchers in the 2014 study has found similar results in his own studies (published in **Biological Psychiatry**, 2010). "Using a very sophisticated MRI technique and focusing on specific areas of the hippocampus, he's shown an association between depression and brain changes."

In addition, Dr. Feinstein notes, studies are showing that higher levels of cortisol—a hormone associated with stress and fatigue—are linked to depression. "I think there's fairly robust evidence now to show that depression is a brain disease in multiple sclerosis."

The **interferon-beta medications** that are sometimes used to treat MS (Avonex[®], Betaseron[®], Extavia[®] and Rebif[®]) may be linked to a greater risk of depression, too, particularly for those who have a history of it. Although research has failed to show a strong link between depression and these medications (as noted by Patten, et al, in their study published in **Multiple Sclerosis Journal** in 2005), post-marketing experience led the U.S. Food and Drug Administration and Health Canada to require that prescribing information supplied to physicians carry a warning about a possible risk. If you're taking one of these treatments, it's very important to talk to your doctor about any psychological symptoms you're having, especially persistent feelings of sadness, hopelessness, worthlessness or a lack of interest in the activities

that you previously enjoyed. It is also important to tell your doctor about past episodes of depression you or family members have had. Despite these concerns, Dr. Bombardier says, “People shouldn’t decline taking these disease-modifying therapies out of worry for depression, because the evidence for that is uncertain.” And even if someone does develop depression as a result of taking these medications, that risk probably doesn’t outweigh the benefits, Dr. Feinstein adds. “If someone develops depression on disease-modifying treatment, the current wisdom is, if they’re benefiting from the disease-modifying treatment, we don’t take them off the drug, because the depression can get better. We just treat the depression.”

The good news is that **depression is one of the most effectively treated symptoms of MS.**



Lifting the Darkness

While depression is common and can occur in MS for a variety of reasons, that doesn’t mean it’s “normal” to be depressed simply because you have this disease. No individual or family should have to live with the emotional pain that depression can bring. “Life with MS is hard enough without trying to do it under the weight of depression,” says Dr. Bombardier.

In fact, depression can cause its own disability. “People who have depression as well as MS may have poorer functioning and poorer quality of life. They may have poor relationships. They may be less independent. They may stop working. Depression is associated with people being less adherent to medications—they may take them less frequently or not be willing to start disease-modifying therapies in a timely manner,” Dr. Bombardier says.

In addition, the emotional pain that depression causes can make people feel their physical pain more acutely, says Frederick Foley, PhD, a clinical psychologist and professor of psychology at Yeshiva University in Bronx, N.Y. Dr. Foley is also director of Neuropsychology and Psychosocial Research at the MS Center at Holy Name Medical Center in Teaneck, N.J.

The first step toward feeling better is having a full evaluation. If you’ve been experiencing any of the symptoms of depression for more than a few weeks, it’s worth discussing them with your neurologist. Some of the symptoms, such as difficulty concentrating and fatigue, are hallmarks of depression and of MS, and your doctor will be able to help you take the first steps toward determining their root cause. He or she may refer you to a **psychiatrist, psychologist, social worker** or other counselor for further evaluation or treatment. These professionals have a wealth of resources available to treat depression.

While we need more research to help us understand the best strategies for treating depression, experts typically recommend using a three-pronged approach: medication, **talk therapy** and exercise. “The causes of depression in MS are a bit mysterious. But that shouldn’t take away from the fact that these different things help,” Dr. Bombardier notes.

Three-pronged approach:

1. Medication
2. Talk therapy
3. Exercise

Ann Marie says that starting medication was a big step in helping her feel better. “But even before that, it was claiming the moment and saying to my doctor, ‘You know what? I’m depressed.’”

Psychiatrists (who are medical doctors) can prescribe medication; while they can also provide counseling, they typically will refer patients to psychologists, social workers or counselors. Today’s antidepressant medications are quite effective, although it may take a bit of patience and persistence to find the one that works best with your particular chemistry, and to find the right dose for you. A 2006 study showed that people with MS who are depressed often don’t receive high enough doses to be effective (Mohr, et al, published in **Multiple Sclerosis Journal**). For these and other reasons, your healthcare team will want

to follow you closely and monitor the results, but most people find relief within a few days to weeks when a medication is working for them.

Nevertheless, it’s important to combine medication with counseling; counseling provides an outlet for the many feelings that arise during depression, and enables individuals to begin the problem solving necessary to actively manage life with MS. Research in the general population also shows that results using a combination of treatment approaches are superior to either method alone (see, for example, the study by de Jonghe, et al, in the **Journal of Affective Disorders**, 2001).

One type of talk therapy that research has been found to be particularly effective in people with MS is called **cognitive-behavioral therapy** (CBT). CBT teaches people to more readily identify when they are having negative thoughts, and to replace them with more positive ones. It’s a way of reframing how you perceive something, which in turn changes how you respond to it. “Oftentimes when we’re depressed, we’re thinking in black and white terms, and catastrophizing,” says Dr. Bombardier. “Cognitive-behavioral therapy helps people think differently about what’s going on. It also helps people resume pleasant activities in their lives, and get back on track doing things that are life-affirming for them.”

Research has shown that CBT works well even when delivered by telephone.

A 2011 study of 127 people with MS and depression (Mohr, et al, in the **Annals of Behavioral Medicine**) found that people who received CBT by phone showed significant improvements in mood and quality of life—an important consideration for people who may not be able to come into a therapist’s office regularly, whether due to mobility limitations, access to transportation or some other issue.

Other forms of talk therapy also are useful, though most haven’t been evaluated as thoroughly. Your counselor will work with you to determine what method is best for you. More important than using a specific type of therapy, however, is finding a counselor with whom you feel comfortable.

Self-help groups also can be useful resources for understanding depression and for feeling less isolated by it. However, they are not an adequate substitute for treatment provided by a trained professional.

A considerable body of research demonstrates that exercise is effective in combating depression in the general population. Increasingly, researchers are also finding that it specifically helps improve depression in people with MS. The first study to demonstrate this was done in 1996, when JH Petajan and other researchers at the University of Utah found that after 15 weeks of **aerobic exercise**, not only did measures of physical fitness show improvement, but so did measures of depression. Recently,

small studies have shown that various types of exercise, ranging from treadmill walking to yoga to unstructured physical activity, have improved the moods of people with MS for up to three months.

For Maria Reyes-Velarde who was diagnosed in 2000 and now has secondary **progressive MS**, this came in the form of a small dog named Bon-Bon. “We decided that maybe part of my problem was being alone in the house. Also, I was mostly sitting down, working on the computer, and I was relying more on my scooter to move. So we decided to adopt a dog. And now he makes me get up to feed him. I have to take him out, even though I don’t walk much. I roll in my scooter and he walks around. I started to socialize again with the neighbors who have dogs. Now, I don’t feel that depressed. Bon-Bon has dog play dates and I have more confidence now that I can socialize.”

In addition, a pair of studies done by Dr. Bombardier and his colleagues at the University of Washington in 2013 and 2014 and published by the American Psychological Association showed that when people with MS receive individual telephone counseling about specific ways they can become more physically active, their depression becomes less severe, and their moods improve from week to week. “They might walk; some people might just stand more. They might go to the gym, or swim, or run—whatever they can do,” Dr. Bombardier says. He notes that for 34 percent of the people in his study, their depression severity dropped

by at least 50 percent. And by the end of the study, he says, 30 percent of the people no longer met the criteria for depression—“just by exercising.” Given this evidence, using CBT to promote physical activity could be a powerful method for managing depression in MS.

The other benefits that exercise conveys—to cardiovascular health, bone density, bowel and bladder function, and more—make it an important part of any regimen geared toward better health. Of course, people should consult with their physicians before embarking on any new exercise regimen.

Another approach to treating depression that is gaining more widespread acceptance is **electroconvulsive therapy** (ECT). “ECT is very safe,” says Dr. Feinstein. It is far different than the “shock therapy” that was portrayed in movies decades ago. It uses extremely small doses of electricity to stimulate specific areas of the brain. While there is a small risk that it could trigger a relapse in some individuals with MS, doctors can often predict the likelihood of that happening based on the level of active disease shown on **MRI** (magnetic resonance imaging) just before the treatment. “I find ECT to be effective in MS patients who have not responded to [other treatments],” Dr. Feinstein says.

The important thing is to not let depression go untreated. It cannot be overcome by willpower or determination, and is not a sign of weakness or lack of character. As noted, there’s a high

likelihood that it’s a result of the way MS changes the brain. But because depression is associated with suicidal feelings, it’s imperative not to ignore it or hope it will go away. In fact, depression is more strongly linked with suicide than wheelchair use, vision loss, or any other symptom or result of living with MS. Because depression is so common, people with MS may have as much as 7.5 times the risk of suicide as people in the general population. And with treatment so effective and readily available, no one should have to remain depressed.

Anxiety

Like depression, anxiety is quite common in MS, affecting more than 35 percent of those with the disease—again, a number higher than the general population. People used to believe that depression and anxiety were two sides of the same coin, so to speak, but now these mood changes are increasingly seen as separate disorders.

People with generalized anxiety feel tense and worried much of the time, and often to a greater degree than external events would seem to demand. Other types of anxiety include panic attacks and obsessive-compulsive disorder, but generalized anxiety is much more common among people with MS. That’s not surprising, given the unpredictability of MS. People with the disease may feel great one day but have considerable pain, fatigue or other symptoms the next. And there’s no road map that tells them how much or how fast their disease will progress.

“One of the things I hear very often in relation to anxiety is people saying, ‘Well, what do you expect? You’ve got a disease here that’s affecting young people. There’s no cure. There’s significant physical disability. Of course a person’s going to be anxious.’ But that’s a really simplistic approach to the problem,” says Dr. Feinstein. “I think anxiety, just like depression, is going to be [shown to be] generated by brain changes. It does have a profound effect on a person’s ability to function. We should not just view it as an understandable reaction to a nasty disease. I think for most people, it’s going to be a lot more complex than that.”

“I’m not someone who has a lot of anxiety or ever had a lot of stress. It’s just tasks that you manage and prioritize,” says David Rosen, diagnosed with relapsing-remitting MS in 2016. “But yet, my body has so much anxiety at times I feel like I’m missing something. Something’s going on or I’m forgetting something. And my whole body feels like it’s moving inside very fast. It’s a lot of anxiety now.”

Many antidepressant medications effectively treat both depression and anxiety. Specific anti-anxiety medications can work well for short periods of time, but carry the risk of dependence. CBT and other forms of psychotherapy can be very effective for anxiety disorders. And yoga and meditation can help calm the nervous system and reduce activity in the parts of the brain that govern the stress response. A 2012 study, published by David Mohr, PhD, in Neurology, found

“I think anxiety, just like depression, is going to be [shown to be] generated by brain changes. **It does have a profound effect on a person’s ability to function.** We should not just view it as an understandable reaction to a nasty disease. I think for most people, it’s going to be a lot more complex than that.”



that people with MS who used stress management techniques were less likely to develop new MS brain **lesions** than people who didn’t use such tactics. More research in this area needs to be done before drawing definitive conclusions. Your doctor or mental health professional can help you find the right combination of treatments for you.

Moodiness and Irritability

While people who experience depression and anxiety with MS may feel that they’re stuck in one emotion all the time, other people with MS can have the opposite problem. Family members often report that the person with MS has frequent shifts in mood, seeming peaceful one moment and moody, irritable or angry

the next. While these changes in mood sometimes result from responses to external events, they also can occur without any triggers—an aspect that makes them difficult to understand, both for the person experiencing the mood shifts and for his or her family, friends and colleagues.

This type of moodiness can be part of depression, or it can exist on its own. “Depression is sadness, but it can also be irritability; sometimes you get a combination of the two,” says Dr. Feinstein. “So a loved one starts noticing a change in the person’s behavior. They’ve become a bit more short-tempered or a bit snappy. They do things that are out of keeping with their usual character,” he explains.

Maria began experiencing this after she was diagnosed in 2000. “It used to be that I would just bark when there was an injustice or there was something wrong. The shift became more apparent when I started fighting with my husband without reason. Something that didn’t bother me before all of a sudden became a really big issue and I had very little tolerance for it.”

Irritability and moodiness can also be symptomatic of many other medical conditions, so it’s important to talk with your healthcare team if you experience frequent changes in mood. They can help you understand why these mood changes are happening and, importantly, what can be done about them.

Bipolar Disorder

People who have this condition experience alternating episodes of depression and mania. **Mania** refers to periods of hyperactivity, excessive cheerfulness or irritability, rapid speech and similar symptoms. Extreme changes in energy, activity, sleep and behavior go along with these changes in mood. A person may be having an episode of bipolar disorder if they have a number of manic or depressive symptoms for most of the day, nearly every day, for at least one or two weeks.

Bipolar disorder affects about **13 percent of people with MS**, compared with less than 5 percent of the general population.

Researchers who conducted a study of mood disorders in MS (MG Carta, et al, **Journal of Affective Disorders**, 2013) found that bipolar disorder is often unrecognized by the medical community and as a result is under-diagnosed. They noted that manic symptoms may be seen by the individual as positive periods that offer relief from depression.

Depression and mania (or **hypomania**, a term for episodes of mania that are less intense or prolonged) can sometimes occur with the high-dose corticosteroids

that are often used to treat MS relapses, so it's important to let your doctor know if you have a history of bipolar disorder or depression if he or she is recommending this treatment.

Pseudobulbar Affect

About 10 percent of people who have MS may experience involuntary bouts of uncontrollable laughing or crying. This phenomenon, called **pseudobulbar affect**, or PBA, occurs as a result of the changes that MS causes in the brain. "It appears to be more closely associated with progressive forms of MS," notes Dr. Feinstein.

Sometimes, PBA episodes exaggerate an emotion that a person is feeling; other times, there's no connection at all

between the person's outward display of emotion and how he or she is actually feeling. "It's kind of like the brakes on our emotional expression are worn out," Dr. Bombardier says.

PBA is typically treated with either antidepressants or Nuedexta®, a medication approved in 2010 that is thought to work in the areas of the brain that control emotion. While PBA has not been shown to respond to CBT or other talk-based approaches, medications are usually effective within 48 to 72 hours. Because PBA can be so upsetting to the person who has it, and to his or her family, it's important to seek counseling to learn how to handle these episodes when they do occur.



MOODS MATTER- TO EVERYONE



Moods play a central role in most people's lives, whether or not they have MS. A person's emotional state can influence his or her physical and cognitive functioning. For example, someone who is depressed is likely to feel more fatigued, have difficulty concentrating, and even move more slowly.

People who feel depressed or anxious are often reluctant to participate in social or community activities, which can lead to a sense of isolation, which in turn creates even more depression or anxiety.

Family and personal relationships are affected, as well. Loved ones may be mystified at what they see as a sudden change in attitude, and wonder what they might have done to bring it on. This is true of children as well as adults. Family members also may feel their own spectrum of emotions, ranging from concern to resentment at having to "pick up the slack." And of course family members affected by MS can experience their own sadness, anxiety and even depression.

"It can be very difficult for a partner or spouse to live with someone who's depressed. If you look at the features of depression, which include social withdrawal, irritability, poor self-esteem, lack of sex drive, sleep disturbance, changes in appetite, one can readily see how symptoms like that can spill over and affect family members as well," says Dr. Feinstein. "Spouses and partners will tell me that this is not the same person

that they married, and they don't know where the change has come from. To them, multiple sclerosis is a disease of walking or of balance or of vision or—but now they've got someone whose personality has changed, and they struggle to deal with that."

Depression affects children too—especially when it's expressed as irritability, Dr. Feinstein says. "Kids may be struggling to understand why Dad is changing. Why has he become so angry? Why is he snapping? The whole dynamic within the family can change and depression can produce significant crises within families."

These changes were difficult for David's family—particularly before his official diagnosis of MS. But recognizing and acknowledging the changes has helped them cope and move forward.

"There were times when my anger was out of control. That's not typical of me," David says. "It's sad that my family had to see the anger that I've portrayed at times, but now that I know it's part of a disease and I have a little more recognition of how I'm acting, honestly I think the relationship with my wife has gotten much stronger."

Staci, David's wife, has learned to give him space. "I understand that he's going through a lot. And sometimes it's like, you learn not to react. Now I kind of just have to take a step back and realize, he's just going through something."

Since MS affects the whole family, it's important to keep lines of communication open, and also to consider family counseling. The Society in the United States and Canada have tools to help you discuss MS with your family and age appropriate literature for children.

Employers may notice a drop in attendance, productivity or your ability to stay focused on a task. Your enthusiasm for your work may also be noticeably different. A recent study of working people with MS found that 14 percent reported absenteeism—missing work due to health problems—and 47 percent reported “presenteeism”—impairment while working. People lost more work time (12 percent) due to working at less than full capacity than they did due to simply not showing up (4 percent lost time). According to the researchers, statistically significant correlations were found between presenteeism and increasing disability, fatigue, depression, anxiety and reduced quality of life add in after life (Glanz, et al, **Value in Health**, 2012).

Perhaps most importantly, mood shifts can affect your ability and willingness to either initiate treatment for your MS and its symptoms, or to adhere to the treatment plan. That can have long-lasting results in terms of your disease course.

For that reason and all the others discussed, it's important to have a self-care routine.

It may be easier during challenging times to exercise, attend a support group, have a weekly date night, cook nutritious meals, meditate, pray, listen to music, take bubble baths, or whatever makes you feel nurtured, when you already have a routine in place. And the payoff of doing them can be enormous—helping to relieve the stress of living with MS, and keeping you engaged in your life and your treatment. If you find yourself not doing the things that have typically given you pleasure, it might be appropriate to ask yourself if you're depressed.

Ann Marie says that when she looks back, she realizes that, in addition to taking her antidepressant medication, one of the most helpful practices for her was writing in her journal, which she used to vent about what was happening to her. She recalls writing about how certain friends were making her feel, as well as things at work that upset her. She wrote when her legs and hands hurt. “A lot of my writing went into this whole ‘what bothers Ann Marie,’ both physically and emotionally,” she says. “I was writing just to talk about how I felt in the moment. So in the very beginning, it wasn't too pleasant. It was very angry. But then it changed. As the months went on, it became very positive.” Ann Marie says that when she began feeling better, she put away the old journal and started a new one. “My new book started with: This is the day I try.”



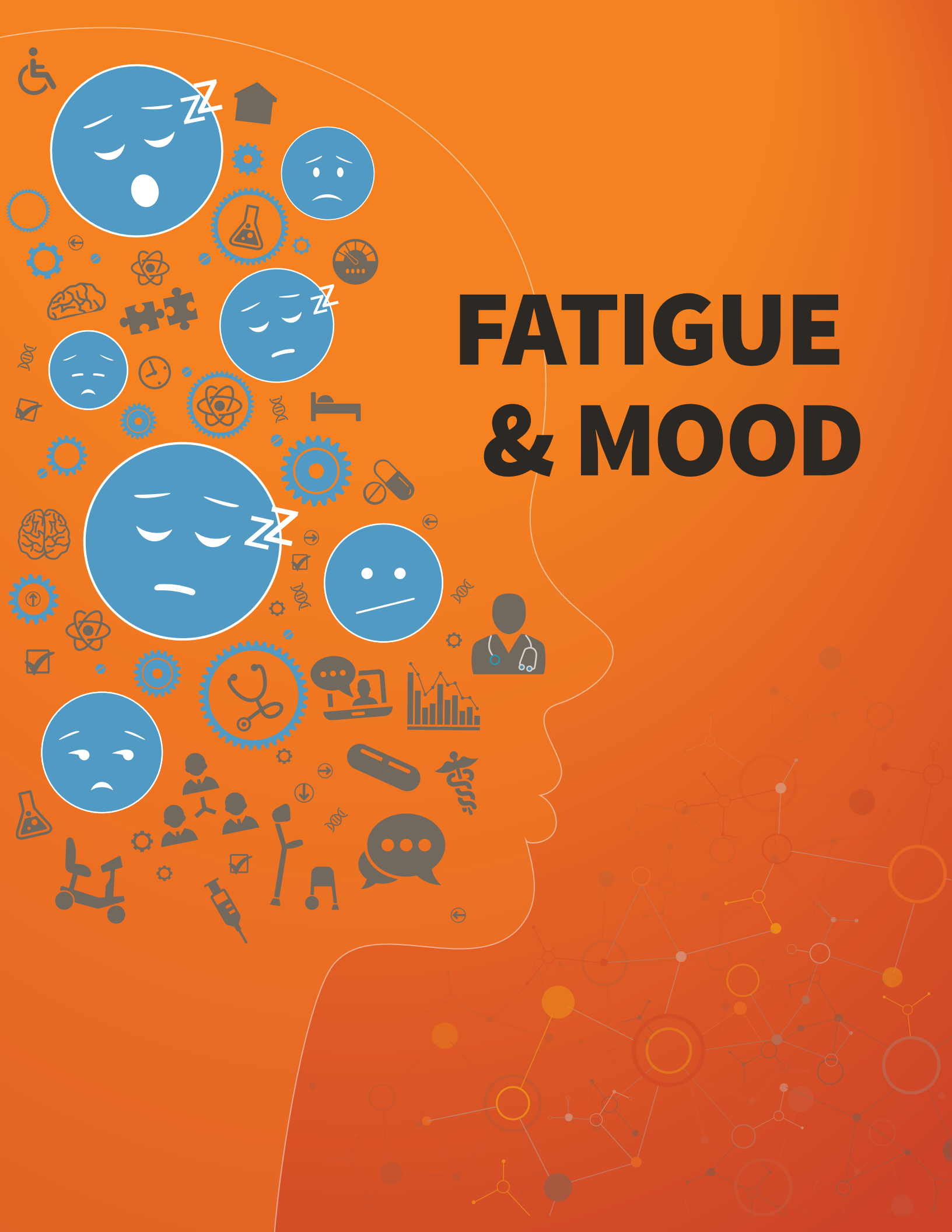
CURRENT RESEARCH

Research is continuing to investigate the causes and most effective treatments for mood changes in MS. A guideline released by the American Academy of Neurology (AAN) in 2013 (and reaffirmed in 2016) underscored the need for this ongoing scientific inquiry when it reviewed 115 existing studies on emotional disorders in MS, and found that there was insufficient evidence to recommend or to discourage use of any particular treatment—pharmaceutical or otherwise—for mood disorders in MS. The AAN also concluded that more research has to be done so that clinicians have a greater certainty that the diagnostic tests and screening tools they’re using are correctly identifying people who would benefit from treatment.

“We really need more well-controlled, randomized clinical trials to determine how effective antidepressant therapy is in MS, and if we need to give different doses of anti-depressants, or different combinations of anti-depressants in persons with MS,” says Dr. Foley. In addition, he says, “Developing valid and reliable screening tools is very important to detect these problems in persons with MS.” With improved diagnostic tools, “People with MS can get screened, properly assessed, and treated for these problems.”

As researchers continue to examine the effects of counseling, medication, exercise and more, there is great hope that we will soon have the answers at hand.

FATIGUE & MOOD



Fatigue is one of the most prevalent symptoms of MS, affecting about 90 percent of people with the disease at some point. Fatigue is not just a physical symptom, however; it is also one of the most common symptoms of depression. A change in mood can affect fatigue, and vice versa, ultimately creating changes in social and family relationships, work and self-care.

Because fatigue is an “invisible” symptom, people who lack knowledge about MS may assume that a person with the disease is exaggerating about the degree of his or her exhaustion or, worse, simply being lazy. But it’s important for everyone affected by MS to understand that MS-related fatigue is unlike the kind of tiredness that people without MS may experience after a long day at work; instead, it feels like an overwhelming lack of energy, and may be unrelated to the type or degree of activity a person is participating in. Like most other MS symptoms, it seems to be caused by the changes in the brain that the disease brings; one theory is that the damaged central nervous system must work much harder than it would in a healthy individual to create the same level of functioning. Fatigue appears to affect people with MS equally, regardless of age, gender, length of time since diagnosis or the severity of disease activity.

Fatigue also can be the result of sleep disorders, which are common in MS.

Sleep apnea and **periodic limb movement disorder** (related to restless leg syndrome) seem to occur more frequently in people with MS than in the general population.

Other symptoms common to MS, such as depression and bladder problems, can make it difficult to get a good night’s sleep.

Of course, other factors, such as medications and other medical conditions, can lead to fatigue, so it’s important to have your healthcare team do a complete evaluation. No matter what, it’s important to recognize the effects fatigue may have on other areas of one’s life.

Fatigue and Depression

A depressed person may sleep a lot, or feel too exhausted to leave the house to go to work or engage in activities they usually enjoy. Unfortunately, this can become self-perpetuating, as lack of activity may lead to deteriorating physical health, which leads to even more fatigue and depression, causing a person to engage in less activity. In short, depression intensifies fatigue, and fatigue intensifies depression.

Of course, not all instances of MS-related fatigue will lead to depression, notes Dr. Lauren Krupp, who leads the NYU Langone's Multiple Sclerosis Comprehensive Care Center. "There are plenty of people with MS who are not depressed, and yet have this severe sense of exhaustion. However, you can easily imagine how, if you feel vulnerable, at the mercy of forces that you can't control, it can make fatigue much worse. So it's very important to try to control the disease, and not let the disease control you. That's an approach that can be very life-affirming and can be helpful in minimizing fatigue."

If fatigue does lead to depression, it may take treatment with an antidepressant medication to break out of these cycles, but usually the treatment is quite effective; research has shown that treating depression can improve cognition (Demaree, et al, **Cognitive Neuropsychiatry**, 2003) and fatigue (Mohr, et al, **Psychosomatic Medicine**, 2003)—and then people can take better care of themselves.

Managing Fatigue

The bottom line is that fatigue and mood appear to be interrelated. For these reasons, anyone who experiences worsening fatigue should be evaluated by his or her healthcare team, so the contributing factors can be identified and addressed before they begin to impact other areas of one's life.

"Most people with MS find that **their energy level wanes as the day wears on**, particularly in the afternoon," Dr. Krupp says. So the earlier part of the day may be the best time to do the most demanding tasks. People should also **consider taking breaks throughout the day to refuel**.

"In contrast to people who don't have MS, the person with MS is working with a gas tank that is half full. So they've got to be very judicious in how they spend that gas."



A comprehensive treatment plan may include lifestyle changes. For example, "We know that exercise helps fatigue," says Dr. Krupp.

Another important lifestyle measure is energy conservation. For many people, that means thinking about when they feel their best.

Dr. Krupp notes that a technique called mindfulness—a way of learning how to approach thinking in a positive way and focus on the present—can also be beneficial. “A very exciting study was published in one of the key neurology journals showing that mindfulness, when used by people with MS, was associated with a significant reduction in their fatigue” (Grossman, et al, **Neurology**, 2010).

Depending on individual circumstances, some medications, such as amantadine or modafinil (Provigil) may be useful for treating fatigue. Treatment options vary according to the cause and type of fatigue a person is experiencing. The Patient Centered Outcomes Research Institute is funding a randomized, double-blind, placebo-controlled clinical trial at the University of California, San Francisco, to evaluate the effects of several drugs in reducing fatigue—and improving the quality of life—in patients with MS, which at the time of print, is in progress.

Summary

Mood plays an important role in how a person feels, and how well he or she is able to interact with the world and participate in his or her own life. Any changes to mood should be addressed separately and collectively. The role of fatigue in these changes should also be considered.

Unlike physical changes that occur in the disease, such as visual disturbances or gait difficulties, mood changes are not readily apparent to others. That’s why it’s helpful to know your body, spirit and mind, and speak up when something is different. As with physical symptoms, the earlier these are diagnosed, the more successfully you’ll be able to manage them—and live your best life.

Resources

United States Resources

The National MS Society has an extensive library of resources about MS, including publications about treatment options, symptom management and living well with MS.

The Society's MS Navigators also offer assistance in answering questions about living with MS. These highly skilled professionals can help you connect to resources in your community, access optimal healthcare, meet workplace challenges, understand health insurance, plan for the future and much more. Whether you are a person living with MS, a family member or someone who cares about a person with MS, you can call an MS Navigator at 1-800-344-4867 during standard business hours, Monday through Friday. You can also email us at contactusnmss@nmss.org or find us on Facebook at [facebook.com/NavigatorMS](https://www.facebook.com/NavigatorMS).

The following articles and brochures, available online or by calling 1-800-344-4867, may prove especially helpful in learning more about how mood, fatigue and cognitive changes interact with a person's experience of MS.

The companion video, **Managing Mood in MS**, is available online at [nationalmssociety.org/video](https://www.nationalmssociety.org/video) by calling 1-800-344-4867.

Mood

Emotional Health **([nationalmssociety.org/emotionalhealth](https://www.nationalmssociety.org/emotionalhealth))**

An overview and links to more in-depth discussions about how MS can affect mood and the expression of emotions, and information about the steps to getting help.

Depression **([nationalmssociety.org/depression](https://www.nationalmssociety.org/depression))**

An overview and links to more in-depth discussions and videos about depression in people with MS. It provides information about how to distinguish depression from normal grieving and how it may be treated.

Suicidal Feelings

Severe depression can be a life-threatening condition because it may include suicidal feelings. One study found that the risk of suicide was 7.5 times higher among persons with MS than the general population. If you are having thoughts about harming yourself or feel you are at risk of hurting yourself or someone else, call the National Crisis Hotline at 1-800-273-TALK (8255) or text "ANSWER" to 839863.

The Shifting Tides of Moods in MS **([MomentumMagazineOnline.com](https://www.momentummagazineonline.com))**

Grief, depression, anxiety and shifting moods are common emotional symptoms in MS. This article discusses why they occur and what to do about them, including tips from experts and people living with the disease.

Fatigue

Fatigue
(nationalMSSociety.org/fatigue)

An overview and links to in-depth information about how MS can affect fatigue, and information on how to manage it.

Fatigue: Take Control
(**video and program**)
(nationalMSSociety.org/video)

An extensive look at how medicine, exercise, managing your environment and making proactive energy choices can help to manage the fatigue associated with MS.

Comprehensive Wellness

Stress
(nationalMSSociety.org/stress)

An overview and additional information about the impact stress can have on MS and information on how to cope.

Live Fully, Live Well
(nationalMSSociety.org/livefullylivewell)

A comprehensive wellness program from the National MS Society and Can Do MS[®], designed for people living with MS and their support partners. **Live Fully, Live Well** covers topics affecting the whole family living with MS in order to strengthen relationships, increase understanding and promote improved health and quality of life.

Everyday Matters
(nationalMSSociety.org/everydaymatters)

The National MS Society's Everyday Matters, supported by Genzyme, a Sanofi company, was an interactive national project that uncovered stories of real people facing—and meeting—the everyday challenges that MS can bring on the path to one's best life.

Educational videos
(nationalMSSociety.org/educationalvideos)

The Society offers a variety of online educational programs, including MS basics, symptom management, relationships, employment and research. Transcripts and podcasts are available for most programs.

Canadian Resources

The Multiple Sclerosis Society of Canada offers many helpful resources. The following publications are available by calling 1-844-859-6789 to speak with an MS Navigator or online at mssociety.ca/resources/library.

MS and Your Emotions

This booklet explains the effects that MS may have emotionally and psychologically on individuals. It describes common reactions to chronic disease and the usual stages of adjustment to MS in a positive and easy-to-understand manner.

Living Well with MS: Mind Matters

This resource helps people understand the connection between MS and depression, and provides solutions that may help to manage depression and improve quality of life.

Living Well With MS: Managing Fatigue

This booklet includes information on the impact of MS fatigue, its causes and diagnosis, as well as a section on different strategies and medications for managing this common symptom.

Fatigue and MS (information sheet)

Fatigue can be one of the most disabling symptoms of MS. According to some studies, more than 90 percent of people with MS experience fatigue.

Additional Reading

The following resources may also be useful:

Facing the Cognitive Challenges of Multiple Sclerosis, 2nd edition;

Jeffrey N. Gingold; 2011, Demos Health

Improving Your Memory for Dummies;

John B. Arden; 2002, Wiley Publishing

Mental Sharpening Stones: Managing the Cognitive Challenges of MS;

Jeffrey N. Gingold; 2009, Demos Health

MS and Your Feelings: Handling the Ups and Downs of Multiple Sclerosis;

Allison Shadday, LCSW; 2006, Hunter House

The MS Workbook: Living Fully with Multiple Sclerosis;

Robert T. Fraser, et al; 2006, New Harbinger Publications

The Stress and Mood Management Program for Individuals with Multiple Sclerosis;

David Mohr; 2009, Oxford University Press

Staying Smart (stayingsmart.org.uk)

Website designed for people who want to know (or know more) about how MS can affect thinking.

Glossary

AEROBIC EXERCISE – A type of physical exercise that increases heart rate and respiration.

ANXIETY – An emotional state characterized by tension, worry, nervousness or uneasiness, often out of proportion to external events. About 35 percent of people with MS experience anxiety.

ATTENTION AND CONCENTRATION – Broadly, these terms refer to the ability to filter out distractions and focus on a task or information.

BIPOLAR DISORDER – A condition, formerly known as manic-depressive disorder, in which a person alternates between low and high moods, as well as low and high levels of energy. About 13 percent of people with MS experience these changes.

COGNITION – A broad term that encompasses a person's ability to pay attention, process and remember information, plan, organize and reason, among other high-level brain skills. Cognitive impairment, a common symptom of MS, refers to any degree of weakening of those skills.

COGNITIVE-BEHAVIORAL THERAPY (CBT) – A type of talk therapy that focuses primarily on the present, with an emphasis on problem solving. In CBT, people learn how to identify distorted thinking, modify their negative beliefs and behaviors, and relate to others in different, more productive way.

COUNSELOR – A person trained to give guidance on personal, social or psychological problems.

DEPRESSION – A persistent state of low mood that is unaffected by external events or enjoyable interactions. About half of all people with MS will experience a major depressive episode at some point in their lifetimes.

DISEASE-MODIFYING TREATMENT (DMT) – A medication that reduces the frequency and severity of MS attacks by altering the immune response.

ELECTROCONVULSIVE THERAPY (ECT) – A procedure used to treat severe depression that involves passing extremely small amounts of electric current through the brain to produce a small, controlled seizure.

FATIGUE – One of the most common symptoms of MS. MS-related fatigue refers to an overwhelming feeling of tiredness that can occur at any time, regardless of the amount of intensity of activity or sleep.

FINE MOTOR CONTROL – The ability to coordinate muscles, bones and nerves to produce precise movements.

HIPPOCAMPUS – A structure in the brain that's believed to play an important role in both emotion and memory.

INTERFERON-BETA MEDICATIONS – Interferons are a group of natural proteins that are produced by human cells in response to viral infection and other conditions. They were named for their ability to interfere with viruses. Interferon beta is produced mainly by

white blood cells and certain connective tissue cells. Several of the approved disease-modifying therapies use interferon beta to reduce the immune attack in MS.

LESIONS – Plaques, scarring or other damage that occurs in the central nervous system as the result of MS disease activity.

MEMORY – The ability to recall information. There are several types of memory, such as the ability to recall events from the immediate past or from long ago, as well as the ability to recall sequences for performing certain activities, such as tying a shoelace or driving a car.

MOOD – A temporary state that reflects how a person is feeling emotionally at any given time. It may change as a result of external events, thoughts or physical concerns.

MRI – Short for magnetic resonance imaging, an MRI is a test that uses a magnetic field to produce an image of the brain, spinal cord or other parts of the body. It's currently the most reliable means of detecting MS lesions.

PROGRESSIVE MS – In very general terms, refers to MS that gets progressively worse over time, without relapses and remissions.

PSEUDOBULBAR AFFECT – A condition in which people experience involuntary bouts of uncontrollable laughing or crying that are unrelated to their mood. This occurs in approximately 10 percent of people with MS.

PSYCHIATRIST – A medical doctor who specializes in the diagnosis and treatment of emotional disorders, including the prescribing of medication, and may also be involved in research.

PSYCHOLOGIST – A person with a master's or doctoral (PhD) degree with a focus on brain-behavior relationships, who diagnoses and treats emotional disorders and/or conducts research, and is permitted in some states to prescribe medication. Some psychologists specialize in neuropsychology.

RELAPSING-REMITTING MS – The most common disease course—is characterized by clearly defined attacks of new or increasing neurologic symptoms. These attacks—also called relapses or exacerbations—are followed by periods of partial or complete recovery (remissions). During remissions, all symptoms may disappear, or some symptoms may continue and become permanent. However, there is no apparent progression of the disease during the periods of remission. At different points in time, RRMS can be further characterized as either active (with relapses and/or evidence of new MRI activity) or not active, as well as worsening (a confirmed increase in disability over a specified period of time following a relapse) or not worsening.

TALK THERAPY – A general term for a range of techniques used in counseling, during which people may discuss their emotions and behaviors.



**National
Multiple Sclerosis
Society**

Our mission is that people affected by MS can live their best lives as we stop MS in its tracks, restore what has been lost and end MS forever.

nationalMSSociety.org

1-800-344-4867

Published in partnership with:



Our mission is to be a leader in finding a cure for multiple sclerosis and enabling people affected by MS to enhance their quality of life.

mssociety.ca

1-800-268-7582