



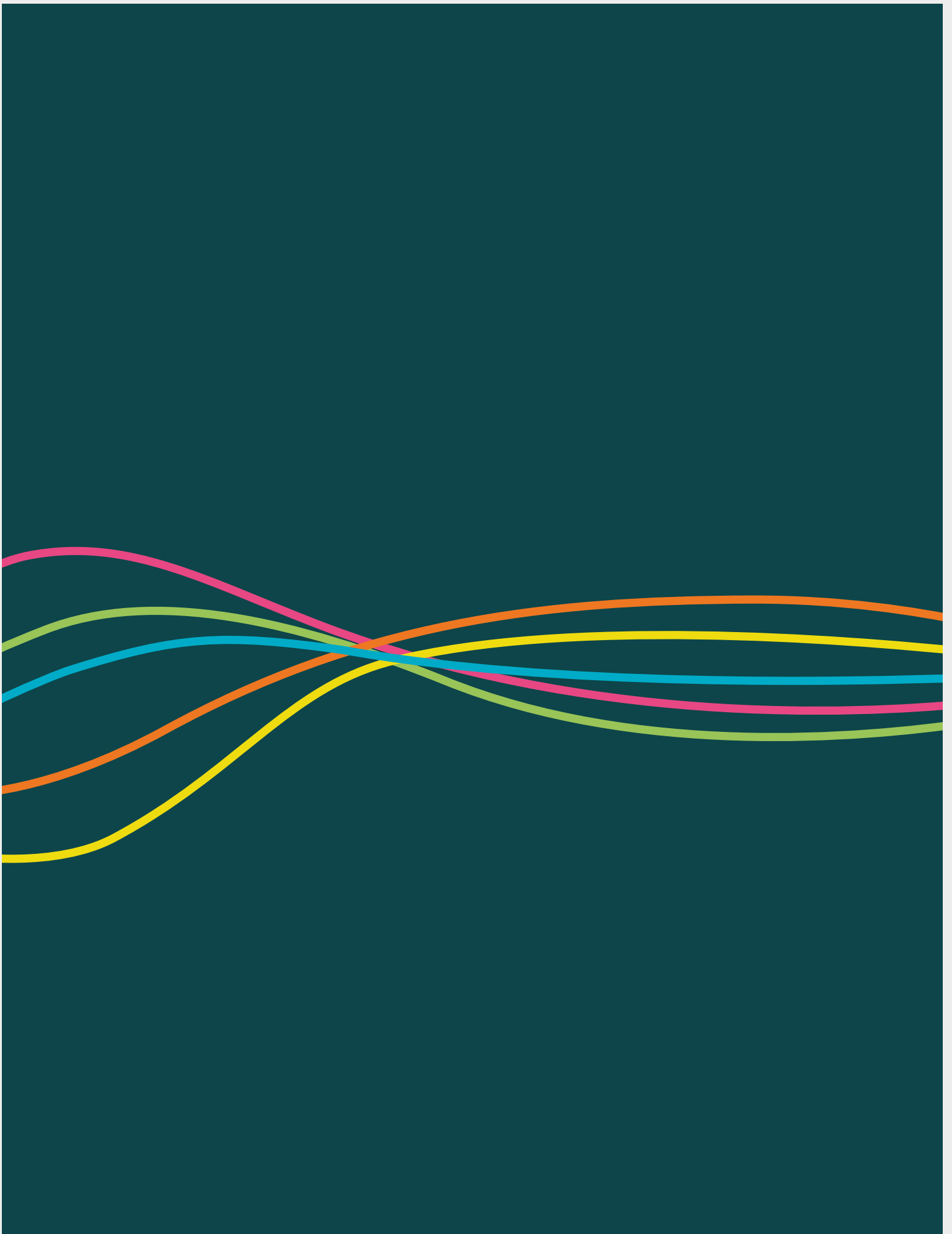
**MOOD &  
COGNITION  
IN MS:**  
[ WHAT YOU CAN DO ]



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Multiple  
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# ACKNOWLEDGEMENTS

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

- Glenn & Rhondell Domilici
- Ann Marie Johnson
- Maria Reyes-Velarde



# PROGRAM STAFF

## **LAURIE BUDGAR**

Editor, Momentum  
National MS Society

## **CATHY CARLSON**

Associate Vice President,  
Research Information  
National MS Society

## **BETH CLARK**

Senior Marketing Manager  
National MS Society

## **ROSALIND KALB, PHD**

Vice President,  
Clinical Care  
National MS Society

## **KIMBERLY KOCH, MPA**

Vice President,  
Programs & Services  
National MS Society

## **NANCY LAW, LSW**

Executive Vice President,  
Programs & Services  
National MS Society

## **SYLVIA LEONARD**

President, Ontario and Nunavut Division  
National Vice President,  
Programs & Services  
MS Society of Canada

## **DORIS LILL**

Client Education Manager  
National MS Society

## **JENNIFER McDONELL**

Information Specialist  
MS Society of Canada

## **MARK SERRATONI**

Creative Services Director  
National MS Society



# PREFACE

**WELCOME TO THE 2014 NORTH AMERICAN EDUCATION PROGRAM,**  
**Mood & Cognition in MS: What You Can Do**, produced by the National MS Society  
in collaboration with the MS Society of Canada.

Our understanding of the role that **mood** and **cognition** play in a person's experience of multiple sclerosis has expanded dramatically in recent years. We now understand that both these types of “invisible symptoms” can be a direct result of the disease process, and can change over time.

We also now recognize that while changes in mood and cognitive abilities 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, and the scientific community is making great strides in identifying cognitive impairment and providing new tools for helping people minimize its presence in their lives. With the appropriate strategies and tools in place, people with MS can live their best lives and participate actively in their own care.

Our program this year explores why and how people with MS experience changes in mood and cognitive functioning, and provides 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 program booklet provides an overview of the types of mood changes common to MS, as well as the types of cognitive challenges that people with MS may face. It 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 want to thank Bayer HealthCare; Genentech; Genzyme, a Sanofi company; Mylan; Novartis Pharmaceuticals; Questcor Pharmaceuticals, Inc.; and Teva Neuroscience for providing generous educational grants to make this program possible.

We hope you will find the program informative and engaging. For further information, visit [nationalMSsociety.org](https://www.nationalMSsociety.org) or [mssociety.ca](https://www.mssociety.ca), or call 1.800.344.4867 (U.S.) or 1.800.268.7582 (Canada).

Best Regards,

**NANCY LAW**

Executive Vice President, Programs & Services, National MS Society

**SYLVIA LEONARD**

President, Ontario and Nunavut Division

National Vice President, Programs and Services, MS Society of Canada



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# PROGRAM GOALS & OVERVIEW

## THOUGH CLINICIANS NOTED MOOD AND COGNITIVE CHANGES

associated with MS as early as the 19th century, these symptoms have only recently begun to receive the same degree of attention from clinicians as physical symptoms.

We now understand that mood, cognition 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.

This year's North American Education Program shines a light on mood and cognitive changes. It is our hope that by discussing them thoroughly and openly, people living with MS, along with their loved ones, will understand that these symptoms are both common and manageable. The expanded understanding of how and why these symptoms occur—as well as recent advances in treating them—are enabling more people with MS to continue to stay engaged in their lives and in their healthcare.

In this book and the accompanying video, you'll hear why these symptoms arise, how to recognize them and, importantly, strategies for managing them. You'll hear from leading experts in MS research as well as people living with the disease.

Understanding and addressing these changes is the first step in becoming empowered to live a fuller, more productive and more satisfying life.

# PERSONAL STORIES

## 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. She has also experienced cognitive changes, including short-term memory lapses and slowed processing speed. 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.

# 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.”

# GLENN & RHONDELL DOMILICI

[ DIAGNOSED WITH RELAPSING-REMITTING MS IN 2005 ]



Glenn lives in New York City with his wife, Rhondell. Glenn formerly had a career in finance, but stopped working in 2009 due to difficulty with dexterity. Shortly thereafter, he began experiencing MS-related challenges with cognition. Glenn manages these challenges by using compensatory strategies (like repeating important information), timers and electronic reminders. He also enjoys technology-based “brain games” that exercise his mind. He is an avid photographer, a self-proclaimed technology junkie, and enjoys cooking. Glenn and Rhondell enjoy going out with family and friends to try new restaurants, and walking in the city.





# 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.



## JOHN DELUCA, PHD

John DeLuca, PhD, is the senior vice president for Research and Research Training at Kessler Foundation in West Orange, N.J., and a professor in the Departments of Physical Medicine and Rehabilitation and Neurology/Neurosciences at Rutgers New Jersey Medical School. He is a licensed psychologist in the states of New Jersey and New York. Dr. DeLuca is a National MS Society-funded researcher. He has been involved in neuropsychology and cognitive neuroscience research for more than 25 years. He is internationally known for his research on disorders of memory and information processing in people with a variety of conditions, including multiple sclerosis, traumatic brain injury, aneurysmal subarachnoid hemorrhage and chronic fatigue syndrome. He has edited two books and co-edited five; in addition, he has written more than 250 publications and book chapters, and is a frequent presenter at scientific conferences and workshops. Dr. DeLuca has won numerous awards for his contributions to the field, including the Rodger G. Barker Distinguished Research Contribution Award from the American Psychological Association in 2012.



### **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 Metro 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 co-directs the adult MS Comprehensive Care Center at Stony Brook Medicine in Long Island, N.Y., where she is a professor of neurology, psychology and pediatrics. She also directs the Lourie Center for Pediatric MS at Stony Brook Long Island Children's Hospital. 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 cognition among individuals living with MS, and has published more than 100 articles on MS.

# MOOD & COGNITION IN MS:

[ WHAT YOU CAN DO ]

INTRODUCTION





## [ MOOD & COGNITION IN MS: WHAT YOU CAN DO ]

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 in cognition, such as difficulty with concentration and **memory**; and alterations in mood, such as **depression** or **anxiety**. These changes are very common.

**ABOUT 60 TO 65 PERCENT OF PEOPLE LIVING WITH MS EXPERIENCE SOME DEGREE OF CHANGE IN COGNITION, AND MORE THAN HALF OF PEOPLE LIVING WITH MS EXPERIENCE MOOD CHANGES AT SOME POINT IN THE COURSE OF THEIR DISEASE.**

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 affects cognition, and vice versa. For example, a person who is depressed is more likely to have difficulty staying focused on a task, may process information more slowly, and will have more difficulty than usual in planning and problem solving. Likewise, a person with memory problems may feel increasingly anxious about forgetting important events, or may become depressed because of his or her changing abilities. In a perpetuating cycle, people who experience changes in cognition or mood may begin to feel out of

place, or unable to keep up, and this can have a substantial effect on self-esteem.

What's more, mood and cognition can make some physical symptoms of MS, such as fatigue or pain, feel worse. Conversely, symptoms like pain can dampen a person's mood. Impaired memory or reasoning skills also can limit a person's ability to manage physical symptoms such as incontinence or balance issues, and they can alter a person's ability to adhere to a treatment plan, as well.

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 mood and cognition helps people with MS better manage their physical symptoms, participate in their own care, and create a more empowered life.



[ PART ONE ]

# MOOD





## [ MOOD ]

Moods reflect 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.

### BUT WHEN MS ENTERS THE PICTURE, IT OPENS UP A WHOLE NEW RANGE OF EMOTIONAL EXPERIENCES.

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. In addition, mood changes can occur as part of the disease process, depending on what parts of a person's brain are impacted. 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, cognition 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. Dr. Bombardier says, however, that people don’t necessarily experience the “five stages of grief” that many people have been taught. 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**—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.

**DEPRESSION, HOWEVER, IS PERSISTENT AND UNAFFECTED BY EXTERNAL EVENTS OR ENJOYABLE INTERACTIONS.**

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.

For Ann Marie Johnson, 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. In fact, about 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.

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.

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<sup>®</sup>, Betaseron<sup>®</sup>, Extavia<sup>®</sup> and Rebif<sup>®</sup>) 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 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 benefitting from the disease-modifying treatment, we don’t take them off the drug, because the depression can get better. We just treat the depression.”



## 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 GOOD NEWS IS THAT DEPRESSION IS ONE OF THE MOST EFFECTIVELY TREATED SYMPTOMS OF MS.**

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.

Ann Marie Johnson 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 MDs) 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** training, 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, a woman from Long Island, N.Y., with secondary-progressive MS (first diagnosed in 2000), 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 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.”

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 that people with MS who used stress management techniques were less like 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 Reyes-Velarde began experiencing this after she was diagnosed with relapsing-remitting MS 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. **Bipolar disorder** affects about 13 percent of people with MS, compared with less than 5 percent of the general population. 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," Dr. Feinstein notes.

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.

**IN FACT, MOODS AFFECT OUR OVERALL QUALITY OF LIFE.**

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 your 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.”

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 Johnson 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. In December 2013, the American Academy of Neurology (AAN) 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.

[ PART TWO ]

# COGNITION





## [ COGNITION ]

The term cognition refers to the many mental processes the brain performs. These include attention, memory, **information processing**, planning, organization, problem solving, visual and **spatial perception**, and language use. The injury to nerve cells and fibers that MS causes can interrupt the “network” in the brain that helps people pay attention to, process and remember information.

People with MS who experience cognitive difficulty sometimes say they feel as if their intelligence has decreased, says John DeLuca, PhD, a psychologist who is the senior vice president for Research and Research Training at Kessler Foundation in West Orange, N.J., and a professor in the Departments of Physical Medicine and Rehabilitation and Neurology/Neurosciences at Rutgers New Jersey Medical School.

**BUT USUALLY, DR. DELUCA SAYS, INTELLIGENCE IS NOT IMPAIRED.**

Information processing, or the ability to hold and manipulate information in the brain, is often the first aspect of cognition to be affected in MS. The ability to process information begins with correct input of the information, gathered through the five senses. Most frequently, however, problems in this realm involve slower processing speeds. “People with MS frequently complain of memory problems,” Dr. Bombardier notes. “But simultaneously, they complain of thinking more slowly. They say they feel like their brain is trying to think through molasses, or the gears in their mind are not turning as quickly as before.”

In daily life, this can show up as difficulty tracking complex conversations or information that is coming from more than one source at a time. Maria Reyes-Velarde,

who was trained as a physician but no longer practices, recalls a time when she and her husband were talking about an incident with her mother’s care. “My husband said, ‘They should have done this, this, this and this.’ Even though I knew those were the [right] things, he was saying them so fast that I couldn’t process it all at the same time. I had to say, ‘Hold on a second; I need to write that down so I can think about it and then be able to talk.’”

People with processing problems also may have frequent difficulty finding the precise word they want to use in a conversation, even though they know it—a heightening of the common “tip of the tongue” phenomenon. “People often say that they eventually do find the right words; it just takes more time,” says Dr. DeLuca. For some people, however,



**verbal fluency** can become significantly impaired. Individuals may stammer as they search for the right word, have difficulty stringing their thoughts together, or they may get derailed from their initial topic altogether, providing unnecessary or unrelated details when speaking.

Individuals may also find that they accomplish much less in a given amount of time, even though the quality of their work may still be high. Many experts think that impaired information processing plays a role in most of the other cognitive difficulties that may emerge as a result of MS.

**Attention and concentration** are also core components of cognition. If you cannot pay close attention to a task, you're unlikely to perform it well. Likewise, if you can't focus and concentrate on information, you probably will have difficulty trying to remember it later.

There are multiple types of attention, and for people with MS, divided attention, commonly known as multitasking, is frequently affected. For example, trying to drive and follow directions to a new location while a passenger asks questions about an unrelated topic may prove extremely challenging. People may also find it difficult to screen out or ignore distractions, or to resume a task once they do become distracted. In addition, people with MS often find that concentrating for an extended period of time leaves them feeling exhausted and unable to stay focused, a phenomenon known as **cognitive fatigue**.

**Memory** for long-ago events is typically unaffected in MS, but short-term recall—memory for recent conversations, events and information—is often impaired. Memory function relies on several steps, which include paying attention to information in the first place, and then learning, storing and retrieving that information. Some research indicates that people with MS may have trouble learning new information (DeLuca, et al, **Journal of Neurology**, 2013); other recent studies suggest that people with MS process, learn and store information accurately, though the process may take them longer, or they may need to learn the information several times, or through several methods before they can retain it (Goverover, **Multiple Sclerosis**, 2011). Careful evaluation is important to find out which processes are affected in any individual's ability to remember information. (For more on this, see the section titled, "**Assessing and treating cognitive changes.**")

While memory is the most frequently reported cognitive difficulty among people with MS, it usually is not a severe problem. According to a review of memory studies, about 40 percent of people with MS either have mild impairments or no memory problems at all. Another 30 percent show moderate disruption of memory skills, and 30 percent have severe difficulty.

Spatial perception involves judging distances and dimensions, and recognizing objects. Perceptual skills can be impaired even if a person's vision is fine; it has to do with the way the brain processes and interprets the information it receives. In daily life, people

who have perceptual impairments may find it challenging to read maps, find their way in an unfamiliar place, or determine the best way to pack the trunk of a car – or even pack a food container with leftovers. A task that involves spatial perception on many levels, such as driving a car, can be overwhelming.

**Executive functions**, such as abstract reasoning, planning, organization and problem solving, can become challenging for people with MS. They may have difficulty understanding the consequences of actions, or setting short-term goals to achieve a longer-range objective.

**Abstract reasoning** involves many components, including:

- Understanding how facts and circumstances are similar or different. For example, if you're visiting a friend in a new city, her local supermarket may be arranged differently than yours, but you can probably figure out, based on all the other supermarkets you've been to, that the produce will be somewhere near the front of the store.
- Understanding humor and sarcasm, which often rely on alternate meanings or contexts.
- Understanding multiple perspectives or aspects of a situation, such as complex current events or political debates.

People with planning and organization difficulties may:

- Lose track of kids' schedules.
- End up driving in circles when running errands, if they don't plan each stop based on its location.

- Forget to pack a lunch to bring to work, and only realize it when their stomachs begin grumbling around mid-day.

- Forget to go to the grocery store in the first place. They don't anticipate being hungry later –so they don't think about all the steps involved in getting food on the table: planning meals, writing shopping lists, traveling to the store, purchasing the necessary ingredients, taking them home and putting them in the refrigerator or pantry, and then beginning to prepare them before meal time.

Many times people with planning difficulties become overwhelmed by the number of steps or simply overlook some of them.

Ann Marie Johnson recalls her attempts to do laundry when her depression made concentration difficult. "I would find it hard to complete each step, or I would do it out of sequence," she says, enumerating each point in the process: sorting, washing, drying, folding, putting away. "I would bring my clothes upstairs and just throw them on my bed; then, come time to sleep, I would literally just push the stuff over, realizing I still have to fold it." Even though doing laundry is routine, she says, "I found it really hard to do."

Problem solving can affect everything from finding another route to work if the usual one has a detour, to balancing a budget, fixing a leaky faucet or keeping a difficult client happy.

Some experts theorize that difficulty with executive functioning occurs because



maintaining awareness of numerous options at once is more difficult.

## THINKING ABOUT CHANGES

The brain and the mind are intricately interwoven. The brain—the organ in the head with the tissue and neural connections—houses the mind, which drives thoughts, emotions and personality. Though the brain and the mind are not the same, most people find that both are closely linked to their concept of “self.”

**“HUMANS DON’T HAVE THESE COMPARTMENTS OF MOOD VERSUS COGNITION. THESE ALL WORK TOGETHER,” DR. DELUCA NOTES.**

For this reason, any change in cognitive skills can influence how people feel about themselves, and how they function in the world. A change in cognitive skills can affect:

### **SOCIAL AND PERSONAL RELATIONSHIPS**

If a person has difficulty expressing his or her thoughts, tracking lengthy or complex conversations, or remembering something a friend or family member talked about recently, both people in the relationship can feel frustrated. For Glenn Domilici, a 41-year-old man who was diagnosed with MS in 2005, this became apparent as he and his wife, Rhondell, struggled with his impaired verbal fluency. “I began to notice that when Glenn spoke, his stories would

just kind of go on and on; there wasn’t really a start, middle and end,” Rhondell says. If these kinds of interactions happen often enough, listeners may become irritated and begin to avoid such conversations, leaving people with MS feeling isolated and alone.

### **FAMILY ROLES**

If you previously were the person in your family who planned social engagements, or were responsible for paying the bills or making sure everyone saw the dentist twice a year, those functions may no longer be your strength. You may find that you need to rely on a partner more, which could shift the balance of the relationship so it no longer feels equal. This can lead to resentment and, in some instances, a loss of respect for or trust in the person with MS. In addition, family members may attribute “invisible” symptoms to a lack of effort or a bad attitude, further breaking down positive feelings toward each other.

### **PERFORMANCE AT WORK**

In a recent survey of more than 4,600 people with MS from 88 countries, participants were asked to rate the impact of cognitive challenges on various aspects of life (**MS In Focus**, 2013). On a scale of 0 to 5, with 5 being very high impact, the effect of cognitive problems on work and employment was rated a 5 by the majority of respondents. In fact, according to a classic study published in **Neurology** in 1991 by Stephen Rao, PhD, and his colleagues, impaired cognitive skills are one of the main reasons people leave the workforce early. A

recent British study found that 64 percent of people who had “retired due to MS” reported cognitive problems. They may find it difficult to initiate a task, manage interruptions, solve a thorny problem, plan and execute a project, or communicate effectively with colleagues. Employers and colleagues may misunderstand what is really happening, and think a person with cognitive challenges is simply careless or sloppy in his or her work. They may not be able to navigate the complexities of public transportation, or to safely drive a car to and from work.

## DRIVING

“If your thinking has slowed down, if your speed of processing information has been affected, if that’s coupled with poor judgment and perhaps a degree of neurological impairment as well, then one can readily understand why driving might be hazardous for certain patients,” says Dr. Feinstein. Inability to concentrate, or distractibility, also can affect driving skills. “You need to maintain some level of focus while you’re driving. If you’re going to be responding to extraneous stimuli in your visual fields, then potentially you’re going to be at risk for having an accident.”

Maria Reyes-Velarde says that for her, the first sign that driving was no longer safe for her was when she was coming home from her son’s house. “At one point, I realized I didn’t know where I was at all.” Making matters worse, she says, “I couldn’t understand what the GPS system was telling me because it kept talking, kept talking.”

## SELF-ESTEEM

For many people, their self-image changes when they realize that their memory or reasoning ability is not as sharp as it once was. “When it comes to mood and cognition in people with MS, we think they’re overlapping conditions,” Dr. Bombardier says. Not only can mood changes such as depression lead to difficulty with cognitive skills such as attention and concentration, but cognitive impairment can lead to mood changes too. People may begin to feel “stupid” or “incompetent,” and value themselves less. In a vicious cycle, these negative feelings can begin to further reduce a person’s sense of mental sharpness.

Sometimes it helps to remember that cognitive abilities, like walking or vision, affect how we interact with the world, but don’t ultimately change who we are in the world. With adaptations, you can continue to engage in the activities and relationships that are important to you, even if you have to do them a bit differently. Glenn Domilici is a photography enthusiast. He now relies on a monopod, automatic shutter releases, lenses with built-in vibration reduction, and software to compensate for his physical and cognitive limitations. “I’m just thankful that through all the tremors and the cognitive issues, MS hasn’t robbed me of my ability to see and take the picture I want.”



## COGNITIVE CHANGES ARE COMMON

It can also help to know you're not alone. Cognitive changes affect up to 65 percent of all people with MS. And it's a symptom of the disease, in much the same way that bladder dysfunction is. While these changes can be embarrassing, they're not a reflection on you as an individual. They don't mean you're losing your mind or your intelligence.

Cognitive symptoms occur independently of physical symptoms—in other words, the degree of physical impairment MS causes, whether mild or severe, has little or no bearing on whether you'll experience cognitive impairment. Cognitive impairment can show up during the early stages of the disease—even as the first symptom of MS—although it's somewhat more likely later on.

Research shows that people with secondary-progressive MS are more likely to develop cognitive dysfunction than people with a relapsing-remitting form of the disease. It seems to be most closely aligned with decreases in the volume of the brain, as shown on MRI (Rao, *International Journal of MS Care*, 2004; Ruet, et al, *Neurology*, 2013). In other words, people with MS who have more cognitive changes also tend to have more (and bigger) MS lesions in their brains and more loss of tissue in both the white matter (which contains the nerve fibers and myelin) and gray matter (which contains the actual nerve cells) of the brain.

Once a person has begun to experience cognitive changes, the changes are unlikely to

disappear; however, they may fluctuate. They may worsen as part of an exacerbation, or flare-up, and subside when the inflammation does. Environmental factors such as heat and humidity, and mood changes such as depression can also make concentration and memory more difficult. Cognition can also worsen temporarily as a side effect of some of the medications used to treat MS symptoms, such as pain, spasticity or bladder dysfunction. This usually occurs shortly after treatment first begins, or when dosing changes. If you're experiencing cognitive symptoms and you've recently started or changed your medications, talk with your doctor to find a solution that's right for you.



## ASSESSING AND TREATING COGNITIVE CHANGES

Sometimes, family members and friends are the first to notice changes in cognitive ability, but may be reluctant to address it with you. It can be a difficult conversation, as few people are eager to acknowledge that their mental capacities have been affected. "I was definitely reluctant to admit that," says Glenn Domilici, who struggles with memory, processing and verbal fluency problems. People also may be worried that if they acknowledge cognitive problems, others will perceive them differently. "If I can't run, you can see that very easily. But if I don't talk, or I just sit back in my chair and let the conversation at the dinner table go on, you may never know that I'm dealing with cognitive issues."

But Glenn's wife, Rhondell, began to suspect something when Glenn's verbal

fluency issues became apparent. “Not that forgetting a word affects your life in any drastic way, but it starts making you realize that brain processes are being affected, and it’s a little scary because you’re not sure where it’s going to go.”

**BUT LIKE MOST PHYSICAL SYMPTOMS, THE EARLIER THAT COGNITIVE CHANGES CAN BE ADDRESSED, THE LESS OPPORTUNITY THEY WILL HAVE TO SIGNIFICANTLY INTERFERE WITH YOUR LIFE.**

It’s important to understand that, while cognitive dysfunction can be a direct result of MS, it can also be worsened—or masked—by other factors common in MS, such as fatigue, depression, pain or even some medications used to treat MS symptoms. “Mood disorders, and particularly depression, can interfere with your ability to think. One of the hallmark symptoms of major depression is impairment in attention and concentration,” says Dr. Foley.

If you are experiencing cognitive difficulties, a visit to your neurologist is in order. He or she can assess the influence of these other factors, and take steps to begin resolving them. If he or she suspects depression, you may be referred to a mental health professional for further evaluation. It’s possible that once you begin treatment for these factors, cognition will improve.

If none of those elements seems to be responsible, your neurologist may refer you to a **neuropsychologist**—a psychologist

with a doctoral degree who specializes in assessing both mood and cognitive abilities—or to a **speech-language pathologist** (SLP) or **occupational therapist** (OT) who has experience with MS for further evaluation.

Because cognition involves so many skill sets, there’s no single brief measure of cognitive function. However, neuropsychologists do have several in-depth tests that can examine information processing speed, several types of memory (such as verbal memory and visual memory), word-finding ability, spatial skills and executive reasoning. You may be asked to memorize a list of words and repeat them back later, or remember where items are on a board, similar to the “Concentration” card game. Other tests may ask you to draw items from memory; name as many items as you can in a certain category in a set period of time; match shapes to numbers using a reference key; perform simple calculations; or perform other similar activities. “They’re largely either computerized or paper-and-pencil tests in which the person is asked questions to determine whether they can learn and remember things as well as they should for a person of their education and age,” Dr. Foley says.

The testing can help identify exactly which processes are most affected in any individual. “Once you’ve processed information, you might know what to do with it, but you may not initiate that activity. Or you may not be as flexible in solving a problem. You might think, ‘This is the only way to solve that problem,’ when in fact there may be two or three ways,” says Dr. DeLuca. Or, he says, you might have more trouble with planning.

“You might know what the right [approach to a problem] is but you can’t plan how to do it. These are very significant problems which are often interpreted by patients or their families as a memory problem. ... And therefore, proper assessment is critical.”

The testing can take six to eight hours, but will usually be broken up over two or more days. Not only can these evaluations assess areas of strength and weakness, but they can also provide a baseline measure—either to compare against periodic assessments in the future, or to assess the effects of a treatment. SLPs and OTs are likely to conduct somewhat shorter evaluations, perhaps lasting two to three hours, and this, too, may be divided into more than one session.

“The importance of a thorough **neuropsychological assessment** is that it will show clearly the person’s cognitive strengths and weaknesses. And the [cognitive specialist] will be able to determine whether or not the person has an impairment present that is likely due to MS,” Dr. Foley states. “And that serves as a template for a treatment plan for rehabilitation. Cognitive therapy is kind of like physical therapy for the mind. Physical therapy isn’t going to make the lesions go away that impair walking ability, and **cognitive rehabilitation** is not going to make the lesions go away that have impaired learning and memory. But physical therapy can significantly improve walking and balance; and cognitive rehabilitation can help a person learn to use his or her cognitive strengths to compensate for areas of weakness. So the neuropsychological

assessment serves as the framework that allows the neuropsychologist or speech pathologist or occupational therapist to develop a remediation plan that is individually tailored to that person.”

Treatment for cognitive symptoms takes several approaches. These include medication, rehabilitation including developing compensatory strategies, and patient and family education.

## MEDICATIONS

Many of the disease-modifying treatments (DMTs) used in MS have been studied, to some degree, for their effectiveness in reducing cognitive symptoms. Unfortunately, cognitive improvement was only noted as a secondary benefit in clinical trials, and did not receive the close examination that a primary goal of a study would. In other instances, study design was less than ideal, so the research on DMTs for preventing or slowing cognitive changes is inconclusive at best.

Some of the medications used to treat the physical symptoms of MS have been studied for their effects on cognition, and to date, the most promising results come from drugs used to treat fatigue (such as amantadine, modafinil (Provigil®) and armodafinil (Nuvigil®).

## REHABILITATION

Cognitive rehabilitation has long been used as part of the therapeutic program for people recovering from traumatic brain injury or stroke. It has a much shorter



history of use—and therefore less data regarding outcomes—in people with MS.

Typically, an OT or SLP will work with a person who has cognitive deficits using one or more approaches. One method attempts to rebuild lost skills through various types of cognitive exercises. These might focus on improving attention (sustained, divided or shifting), memory, processing speed, planning or problem solving. They may start out using computer drills and workbooks and expand into real-life situations.

The success of these techniques relies on a property of the brain known as neuroplasticity, which means that unimpaired areas of the brain can begin to perform some of the functions of the damaged regions after sufficient practice.

One type of drill thought to improve memory is a technique called “self-generation.” With this approach, people learn to periodically quiz themselves about something they want to remember. It is based on the premise that recall is far better when people supply the correct responses themselves rather than having someone else provide the information.

Another technique involves “spaced learning,” in which a person reviews the information multiple times, but with a delay between each learning episode. This seems to work better than a “cram session,” in which all the learning takes place in one extended period of time. “Let’s say you’re reading a newspaper,” Dr. DeLuca suggests. “And you know you have trouble remembering things, so you say to yourself, ‘I’m going to read

this article three times so I get it right.’ We know that if you read it three times, spaced apart by 15 minutes, you will remember the information better than if you just read it three times in a row.”

Studies examining the effect of brain retraining in people with MS have had mixed results. One recent study was promising, however. Researchers at the Kessler Foundation in New Jersey found that a specific type of memory training improves learning in people with MS. The researchers met with study participants twice a week for five weeks and taught them to use the “story memory technique,” which involves using imagery to help remember specific words or concepts, and then linking them all together in a story to further enhance recall. Researchers found that not only did the technique work, but people were able to successfully use it for at least six months after training ended (Chiaravalloti, DeLuca, et al, *Neurology*, 2013).

Another way therapists work with people with MS is by helping them develop techniques to work around their cognitive challenges. For example, you might ask people to give you information in small bits that you can process easily, or warn people up front that you have difficulty remembering conversations and may need repetition.

“Everybody uses compensation strategies to one degree or another,” Dr. Bombardier notes. “It’s just that the person with MS might have to use more or different techniques.”

There are countless other self-directed strategies a person can use to manage

cognitive challenges. For example, if you know you have difficulty remembering appointments, you can use a smartphone or paper calendar to record upcoming events, and a family calendar to keep track of everyone's activities and commitments. Glenn Domilici is a fan of using his iPad tablet to make lists, because his memory is poor and his fine motor skills no longer allow him to write reminders by hand.

You can also make use of environmental cues, such as always taping your grocery list to the door the night before a shopping trip and keeping common items such as keys and glasses in the same storage places so they won't be misplaced. The most important overall strategy may be to substitute organization for memory wherever possible, so you don't have to rely on your memory to get things done. For example, an online banking system can help you keep track of bills and their due dates, and even eliminate the need to remember where you keep the checks, envelopes and stamps.

If you know that following along in a group conversation is difficult, try to limit your interactions to one-on-one, when possible. If you're easily distracted, try to work in a quiet environment and only take on one task at a time. If divided attention is a problem—for example, you can't listen to someone speak and simultaneously take notes on what they're saying—ask the person to email you the most important information, or ask him or her to slow down so you can take notes, as Maria Reyes-Velarde does. Perhaps most important, give yourself permission to do things in new ways. It's not important how

you accomplish something, as long as you are able to continue to do the things that matter to you.

At work, your employer may be able to make certain accommodations, such as permitting a flexible schedule or providing you with computer software to assist with specific tasks. In addition, you may be able to use an organizational system to keep you on track with tasks that need to be performed, meetings and other responsibilities. Likewise, a student may be able to record an instructor's lectures and listen to them repeatedly.

Because each individual has different strengths and weaknesses, as well as different levels of awareness of how cognitive change is affecting his or her life, and different levels of comfort with technology, it's not always easy for people to develop strategies on their own. This is where a speech-language pathologist or an occupational therapist can provide important assistance and help people move forward with their lives.

Physical therapists, too, may one day have a role to play in cognitive rehabilitation. Increasingly, evidence suggests that physical activity can promote healthy brain function. A recent study at the Kessler Foundation found that **aerobic exercise** increased the volume of the hippocampus (a region of the brain responsible for memory and learning) and improved memory for word lists and visual patterns (Leavitt, et al, **Neurocase: The Neural Basis of Cognition**, 2013). Another study, currently underway at the University of

California, Los Angeles, is examining whether aerobic exercise improves information processing as well as memory. Yet another study will investigate whether specific types of exercise are more effective at improving cognition in people with MS.

Regardless of which approach works best for you, it's critical to have support from family, friends and others in your network.

**“HAVING A COGNITIVE PROBLEM IS NOT JUST AN MS PATIENT AFFAIR. IT’S A FAMILY AFFAIR. EVERYONE IN YOUR FAMILY IS AFFECTED BY THIS,” DR. DELUCA POINTS OUT.**

It may be difficult to acknowledge—to yourself and to others—that your mind is not functioning as sharply as it once did, but once it's out in the open, people will be able to understand what's happening to you and why. Once they're on board, they can help you implement strategies to perform at your best, and brainstorm ways to keep things working smoothly and harmoniously, around the house and away.

“Just like you would like to help your daughter if she had a heart problem, your family members want to help you with your cognitive problems,” Dr. DeLuca says. “You should seek help not just from professionals but from your family and friends.”

“I knew my family would always be in my corner. But I also know that I have a core group of friends who are also always going to be in my corner, regardless of my situation,” Glenn Domilici says.

Even so, he acknowledges that his MS affects everyone in his circle. “I know my cognitive issues are probably frustrating for my wife, Rhondell, like when we're at the elevator to leave and I have to run back because I realize that I forgot my phone or something else,” Glenn says. For her part, Rhondell says that despite any frustrations, “The most important thing is for him to know that it's OK with me, whatever it is. He should never have to apologize for the cognitive issues when he's with me.” She adds: “If I had one piece of advice for someone who's a partner to someone who has MS, it would be to be a safe haven, a place where their partner feels safe, and secure to be themselves.”

Not everyone handles the challenges of MS as elegantly as the Domilicis, however. It's important that family members have an opportunity to ask questions about cognitive issues and an outlet to express their own emotions, so they can better support you. They'll have your back, and that makes life more pleasant for everyone. “Rhondell's been like a rock for me,” Glenn says. “And I've learned to ask for help.”



## CURRENT RESEARCH

Cognitive impairment in MS often goes undetected—and therefore untreated—until it becomes quite pronounced. Researchers and clinicians would like to enable people to make positive changes much sooner, but historically, several obstacles have stood in the way.

First among these is that people who have



cognitive difficulties often don't know it. Then, even once cognitive difficulties are noticed, they often are attributed to other symptoms common to MS, such as fatigue and depression. In addition, physicians and patients alike may be deterred by the amount of time it takes for a person to undergo a full neuropsychological battery of tests to tease out the presence, extent and type of cognitive impairment. OTs and SLPs have shorter test protocols that can indicate the need for more in-depth testing, either with them or with a neuropsychologist.

Recognizing the importance of making cognitive assessment more common and less stressful for those living with MS, neuropsychologists too have developed shorter, more practical tools. These include the Rao Brief Repeatable Neuropsychological Battery (BRNB) and the Minimal Assessment of Cognitive Function in MS (MACFIMS). Both tests examine attention, verbal and visual information processing and recall, as well as verbal fluency; the MACFIMS also looks at spatial processing and executive cognitive functioning. The BRNB can be administered in about 30 to 60 minutes, while the MACFIMS takes about 90 minutes to complete. Now, researchers are working to identify specific subtests from these two assessment tools that could be used alone for even more rapid but reliable screening.

Another commonly used test, the California Verbal Learning Test, was shortened from 25 minutes to about three minutes by Dr. Foley's colleagues. "We did an analysis that captured most of the learning problems that occurred in persons with MS. So this allows

this very shortened version of the test to be used as a screening tool in the very busy clinic setting, where a nurse or a neurologist might not have more than two or three minutes to assess cognitive problems in MS," Dr. Foley says.

Even newer developments, such as computer-based testing, may make assessment more common for people who don't have easy access to clinics.

A movement is also underway to make the testing that does happen in clinics more relevant to the challenges people face in the real world. "We're doing that by introducing distractors into cognitive testing," says Dr. Feinstein. "In the middle of testing, the computer might start ringing like a telephone, and [the person will have to] try to avoid the distraction and stay on task ... to simulate the kinds of challenges that individuals can confront in day-to-day life that could completely derail their ability, because we know that people with MS have problems with attention and staying on task."

In addition, researchers at the University of Texas at Austin found encouraging results earlier this year from a screening tool called the PROMIS (Patient Reported Outcomes Measurement Information System). The brief tool asks individuals a series of eight questions about cognitive skills such as concentration and memory, and was found to be an accurate reflection of cognitive functioning. The results of the study, published in the **International Journal of MS Care**, by Becker, et al, also strongly suggested that people with MS who report cognitive

challenges are also the most likely to be depressed, to be unemployed and to believe their functional abilities are impaired.

Researchers also are keen to develop scientifically proven strategies to improve cognitive abilities. Currently, they are attempting to design treatment protocols that teach people to use the spaced learning and self-generation strategies for recall in everyday life. And because processing speed seems to be at the root of many other cognitive abilities, researchers would like to find focused treatments that can improve this function.

Researchers also are looking at possible pharmaceutical treatments, such as one involving estriol, a hormone related to estrogen. Estriol levels rise to very high levels naturally during late pregnancy—a time when MS activity also declines in women. Some researchers theorized that estriol might be responsible for this easing of MS symptoms. To find out, Dr. Rhonda Voskuhl and her team at the University of California, Los Angeles, administered estriol to mice that have an MS-like disease, and found that estriol was indeed protective (**Journal of the Neurological Sciences**, 2009). Next, they conducted a very small study with 12 women, and again found that estriol decreased MS disease activity. An expanded study, funded by the National MS Society, has just been completed at 16 medical centers nationwide and a full analysis of results is underway. In addition, Dr. Voskuhl's team has gone on to show that mice treated with estrogen can develop improved transmission of nerve impulses in the hippocampus (**Laboratory**

**Investigation**, 2012), raising hopes that learning and memory might improve. As a result, researchers are launching a clinical trial to test whether estriol improves cognitive function.

Emerging research is beginning to suggest that “intellectually enriching” activities over the course of one’s lifetime protect against cognitive decline. In 2013, James Sumowski and his colleagues at Kessler (including Dr. DeLuca) published a small study in **Neurology** that showed that people who engaged in cognitive leisure activities such as reading newspapers, producing art, playing a musical instrument or participating in structured games or hobbies, seemed to be able to continue to perform cognitive tasks, despite damage in the brain caused by MS. This effect, called “cognitive reserve,” was most pronounced in protecting memory. Dr. DeLuca says this is one of the most exciting areas of cognitive research because it suggests that “if you maintain an active, enriched lifestyle, you can decrease the symptoms of cognitive problems with MS.”

The authors of the study cautioned that even though they saw an association between these factors, they can’t yet conclude that intellectual activity is the cause of this protection. Some third factor—perhaps something that causes people to engage in this kind of activity—could instead be responsible. And so far, it’s not known whether engaging in intellectually stimulating activities once the damage from MS has already been sustained will improve cognition.

[ PART THREE ]

# FATIGUE

& ITS RELATIONSHIP  
WITH MOOD & COGNITION





## [ FATIGUE ]

If any symptom can be said to be common to almost everyone with MS, it's fatigue. About 90 percent of people with the disease report experiencing it. Not only is this symptom prevalent; its impact is far-reaching because fatigue is inextricably linked with cognition and mood; an increase or decrease in any one of these symptoms affects the others. And each creates change 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 multiple sclerosis 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 MOOD

**IN ADDITION TO BEING A SYMPTOM OF MS ITSELF, FATIGUE IS ONE OF THE MOST COMMON SYMPTOMS OF DEPRESSION (WHICH IS WHY DEPRESSION SOMETIMES ISN'T IMMEDIATELY APPARENT IN A PERSON WITH MS).**

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 directs the Lourie Center for Pediatric MS at Stony Brook Long Island Children’s Hospital, and co-directs the adult MS Comprehensive Care Center at Stony Brook Medicine in Long Island, N.Y., (part of the State University of New York at Stony Brook), where she is a professor of neurology, psychology and pediatrics. “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.

## FATIGUE AND COGNITION

Likewise, fatigue and cognition are intertwined. Many people with MS find that when they attempt to concentrate on something for a long period of time, they feel mentally wiped out.

**THIS PHENOMENON, KNOWN AS COGNITIVE FATIGUE, IS DISTINCT FROM THE MORE COMMON PHYSICAL FATIGUE EXPERIENCED BY SO MANY PEOPLE WITH MS.**

This feeling of cognitive fatigue can occur when you’re paying your bills, for example, and just can’t get your checkbook to balance, or at work, when you can’t solve a thorny problem. It can feel more challenging than it used to, and by the time you’re done, you’re mentally exhausted—as though you have hit a mental wall. This can make the physical fatigue of MS feel even worse—which can, in turn, lead to depression, again linking all three symptoms.

Many people believe that their ability to complete mentally demanding tasks declines when they feel physically drained by MS fatigue. Research, however, suggests that people perform more effectively than they think they do under these conditions—at least in research settings (Beatty, et al, **The Clinical Neuropsychologist**, 2003). In other words, the fatigue that is so common in MS appears to have less of an impact on cognitive function than people think it does, but cognitive fatigue appears to

play an important role in the performance of tasks requiring information processing, learning and other cognitive skills.

“But most people, when they describe fatigue or mental fatigue, are describing a perception of how they feel as opposed to, ‘Gee, I’m slowing down over a five-minute interval.’ So we’re still trying to dissect how that experience of fatigue really translates into real-life functioning,” says Dr. Krupp. “The good news,” she adds, “is that people, under certain circumstances, can get the cognitive task done—if they give themselves enough time, and try to be as calm and non-stressed as possible, and eliminate distractions.”

## MANAGING FATIGUE

The bottom line is that fatigue, cognition and mood appear to be inter-related. 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.

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. “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.”

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 a few years ago 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 will vary according to the cause and type of fatigue a person is experiencing.

# [ PART FOUR ]

# SUMMARY

Mood and cognition each play 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. But neither mood nor cognition exists in isolation; each has a continuous and significant impact on the other. Any changes to mood or cognitive abilities should be addressed separately and collectively. The role of fatigue in these changes should also be considered.

Changes to mood and cognition are both parts of living with MS. Unlike physical changes that occur in the disease, such as visual disturbances or gait difficulties, they're 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.





# ADDITIONAL 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](mailto:contactusnmss@nmss.org) or find us on Facebook at [facebook.com/NavigatorMS](https://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 and cognitive changes interact with a person's experience of MS.

**The companion video *Managing Mood & Cognition in MS* is available by calling 1.800.344.4867 or online at [nationalMSSociety.org/video](https://nationalMSSociety.org/video).**

## MOOD

### **Depression & Multiple Sclerosis** ([nationalMSSociety.org/all-brochures](https://nationalMSSociety.org/all-brochures))

This booklet provides an overview of the symptoms of depression, the relationship between MS and depression, available therapies, and where to find help.



### **Multiple Sclerosis & Your Emotions** ([nationalMSSociety.org/all-brochures](https://nationalMSSociety.org/all-brochures))

This booklet describes the range of emotional reactions and changes that can occur and provides information for individuals with MS and their families on how to recognize, talk about, manage and learn from these feelings.

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

### **Emotional Health** ([nationalMSSociety.org/emotionalhealth](https://nationalMSSociety.org/emotionalhealth))

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

### **Depression** ([nationalMSSociety.org/depression](https://nationalMSSociety.org/depression))

This page provides 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.

## **COGNITION**

### **Solving Cognitive Problems** ([nationalMSSociety.org/all-brochures](https://nationalMSSociety.org/all-brochures))

Discusses brain functions most likely to be affected by MS. Offers self-help and information on cognitive rehabilitation.

### **Lost in Thought** ([MomentumMagazineOnline.com](https://MomentumMagazineOnline.com))

Challenges with concentration, memory, organization, planning, reasoning and judgment are common in MS. Learn the strategies that you and your healthcare team can use to overcome 'cog fog,' including tips from experts and people living with the disease.

## FATIGUE

### **Fatigue: What You Should Know** ([nationalMSSociety.org/all-brochures](https://nationalMSSociety.org/all-brochures))

MS fatigue can be reduced with treatments and self-help.

### **Fatigue: Take Control (video and program)** ([nationalMSSociety.org/video](https://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. Contact the Society to inquire about an upcoming **Fatigue: Take Control** program in your area.

## COMPREHENSIVE WELLNESS

The following resources may help you address mood and cognitive changes as part of an overall strategy for living well with MS.

### **Taming Stress** ([nationalmssociety.org/all-brochures](https://nationalmssociety.org/all-brochures))

A brochure about simplifying daily life. Instructions on muscle relaxation, deep breathing, visualization and more.

### **Live Fully, Live Well** ([nationalMSSociety.org/livefullylivewell](https://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](https://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](https://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.

## **DVDs ([nationalMSSociety.org/DVDs](http://nationalMSSociety.org/DVDs))**

These videos can help you on your personal journey of living with MS. Learn more about health and wellness, research, employment, mobility and accessibility, parenting and more.

## **CANADIAN RESOURCES**

The Multiple Sclerosis Society of Canada offers vast numbers of resources. The following publications are available online at [mssociety.ca/en/help/booklets.htm](http://mssociety.ca/en/help/booklets.htm), or by calling 1.800.268.7582.

### **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.

### **Cognitive Change and MS**

This publication provides comprehensive information about cognitive dysfunction. It also shares practical strategies for coping with this common symptom.

### **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

**MS In Focus: Cognition and MS;**

2013 <http://ntl.ms/MSIFcognition>

**Multiple Sclerosis: Understanding the Cognitive Challenges;**

Nicholas LaRocca, PhD & Rosalind Kalb, PhD; 2006, Demos Health

**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** ([www.stayingsmart.org.uk](http://www.stayingsmart.org.uk))

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



# GLOSSARY

**Abstract reasoning.** The ability to analyze patterns and relationships to solve problems.

**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.

**Cognitive fatigue.** A feeling of mental exhaustion and inability to stay focused that may occur after concentrating for an extended period of time.

**Cognitive rehabilitation.** Treatment provided by a neuropsychologist, occupational therapist or speech/language pathologist to improve the functioning of people with cognitive changes. Rehabilitation strategies are designed to improve impaired functions with repetitive exercises or drills, or to compensate for impaired functions with strategies and tools.

**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.

**Executive functions.** A term that describes several high-level cognitive skills, such as abstract reasoning, judgment, planning, organization and problem solving.

**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.

**Information processing.** A cognitive skill that involves the ability to hold and manipulate information in the brain.

**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.

**Neuropsychologist.** A psychologist with a doctoral (PhD) degree and special expertise in brain-behavior relationships. Neuropsychologists assess, diagnose and treat people across the lifespan with neurological, medical, neurodevelopmental and psychiatric conditions, as well as other cognitive and learning disorders.

**Neuropsychological testing.** A battery of paper-and-pencil tests (sometimes administered electronically) designed to evaluate the impact of disease or physical trauma on a person’s cognitive skills. The test results identify cognitive functions that have changed or declined, as well as those functions that remain intact – information that is useful in cognitive rehabilitation.

**Occupational therapist.** A professional who evaluates and treats a person’s physical and cognitive ability to perform activities of daily living (such as showering, dressing and eating) as well as activities related to work and leisure in a safe and independent manner.

**Physical therapist.** A professional who evaluates and treats physical functioning and mobility in everyday life.

**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 type of MS, in which a person experiences attacks (also called relapses or exacerbations) of worsening neurologic functioning and symptoms, followed by periods of remission, in which partial or complete recovery occurs.

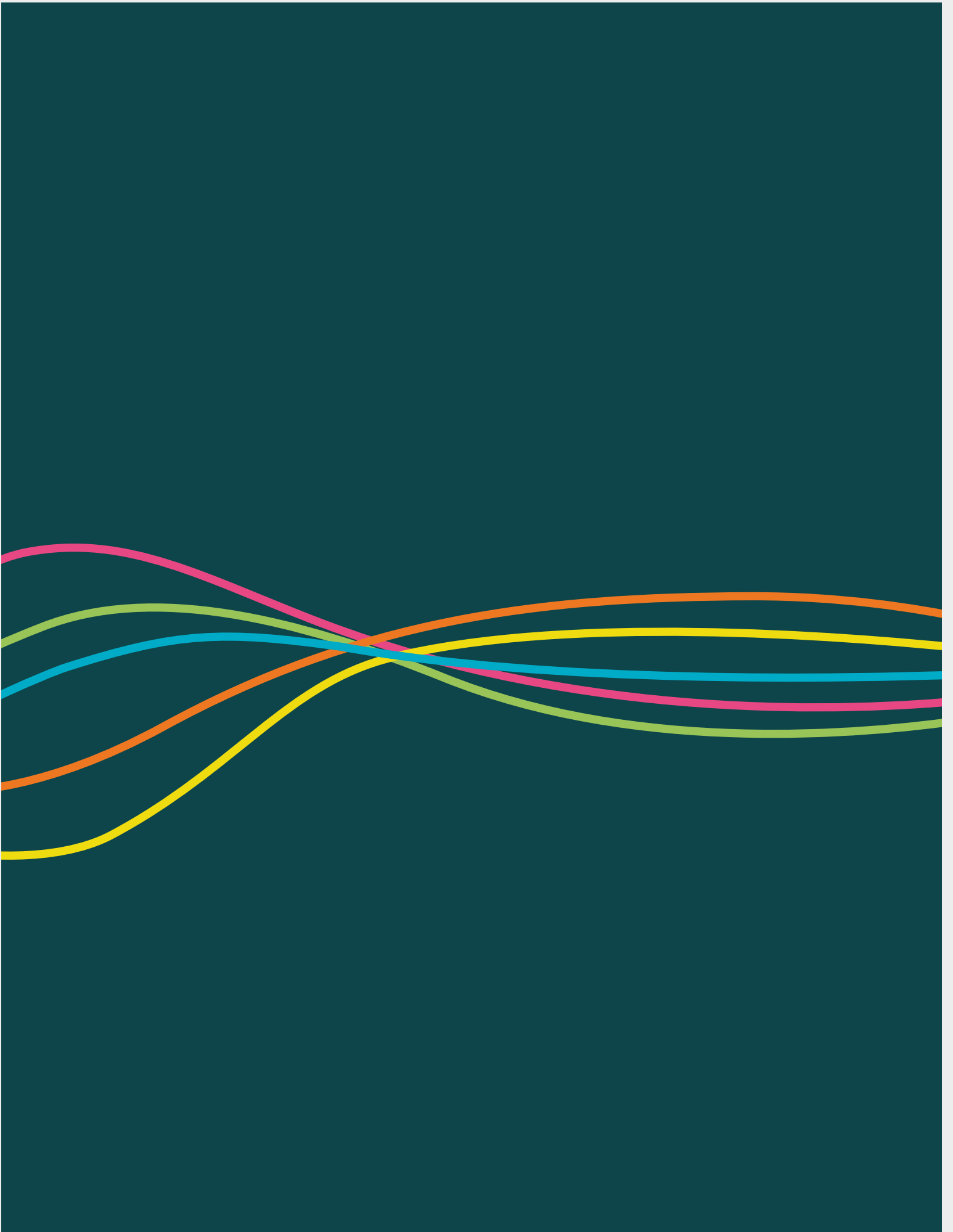
**Spatial perception.** A cognitive skill that involves judging distances and dimensions, and recognizing objects and their relationship to one another in space.

**Speech-language pathologist.** A professional who evaluates and treats problems with speech production or clarity, language use and comprehension, cognitive abilities and swallowing function.

**Talk therapy.** A general term for a range of techniques used in counseling, during which people may discuss their emotions and behaviors.

**Verbal fluency.** The ease and speed with which a person can communicate thoughts in a connected, meaningful way.







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